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Retinoblastoma: The Situation in Burkina Faso over Ten Years

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Abstract

Context: In Burkina Faso, there is only one retinoblastoma treatment center located in the capital. Nowadays, the treatment of retinoblastoma has benefited from the contribution of scientific progress. **Objective:** The aim was to take stock of the situation of retinoblastoma in the pediatric oncology department from January 1, 2010 to December 31, 2019. **Materials and Methods:** This was a descriptive cross-sectional study with retrospective data collection over a 10-year period, based on records of patients admitted to pediatric oncology department of CHU-YO. Data were analysed using CS Pro version 7.2 software. Categorical variables were compared using Pearson's Chi-square test at the 5% significance level. Overall survival was estimated using the Kaplan-Meier method. Operational definitions were used for lost to follow-up, consultation and diagnosis delays. **Results:** We collected a total of 204 cases in 10 years, *i.e.* an annual average of 20.4 cases/year. The mean age at diagnosis was 37.5 months for unilateral cases and 26.4 months for bilateral cases. Male predominance was noted, with a sex ratio of 1.31. The majority of patients came from disadvantaged backgrounds (72% farming fathers and 91% housewives). Clinically, leukocoria and exophthalmos were the main presenting features. The average time to consultation was long (8.73 months) and unilateral localization was predominantly unilateral at 77%. In terms of treatment, 102 patients were eligible for curative treatment and 80 for palliative treatment. The prognosis was poor, with 41% death and numerous cases

of lost to follow-up (18%). Overall survival was estimated at 32%. The factor associated with the lethality of retiniblastoma was the extension of the tumor to other organs. **Conclusion:** Recognition of the early clinical signs of retinoblastoma can anticipate the occurrence of this cancer. Health professionals should be encouraged to perform the Buckner test every time they come into contact with children aged 0 to 5, and the public should be encouraged to examine their children's eyes.

Keywords

Retinoblastoma, Prognosis, Pediatric Oncology, CHU-YO, Burkina Faso

1. Introduction

Cancer, long neglected in Africa, is beginning to attract the interest of development actors because of the growing number of cases and the difficulties involved in treating them. Malignant tumors in children, once considered rare in Africa, are now emerging as a result of more sophisticated diagnostics. Their prevalence is thus contributing to the increase in infant mortality. According to a study carried out in Burkina Faso on malignant solid tumors [1], the number of cancer cases diagnosed has risen steadily over the years.

Retinoblastoma is considered a rare tumor in developed countries, accounting for approximately 3% of childhood cancers and 11% of tumors that develop in the first year of life [2]. Retinoblastoma is the most common malignant intraocular tumor in children. The median age at diagnosis is two years for the unilateral form and one year for the bilateral form [3]. Its overall incidence is estimated at 1 in 15,000 to 25,000 live births, with around 7000 cases each year worldwide, including at least 2000 cases in Africa [4] [5]. The incidence of retinoblastoma appears to be higher in developing countries [6]. In Burkina Faso, retinoblastoma accounted for 12.29% of all childhood cancers in 2009 [1]. It requires early, multidisciplinary management involving radiologists, oncologists, ophthalmologists, paediatricians, pathologists, radiotherapists, oculists, geneticists and psychologists. This multidisciplinary approach results in better outcomes for patients, as well as long-term specialist follow-up [7] [8]. Retinoblastoma treatment in Burkina Faso currently relies mainly on chemotherapy and enucleation [9].

The prognosis is currently excellent in developed countries, with a high rate of therapeutic success. Long-term survival of patients with hereditary forms remains threatened by the risk of secondary tumors.

In low- and middle-income countries such as Burkina Faso, retinoblastoma remains a lifethreatening condition because it is diagnosed at an advanced stage [10]. In recent years in Burkina Faso, there has been an increase in the number of cases of retinoblastoma in the only retinoblastoma treatment center, in a context where the technical facilities are inadequate [9] [11].

In order to gain a better understanding of what is being done, and above all to assess the situation over a 10-year period, we studied the epidemiological, diagnostic, therapeutic and evolutionary characteristics of children with retinoblastoma.

2. Material and Methods

This was a descriptive and analytical cross-sectional study, with retrospective data collection based on consultation of the records of children with retinoblastoma admitted to the pediatric oncology department of the University Hospital of Yalgado Ouedraogo (CHU-YO) from 1 January 2010 to 31 December 2019.

Selection: The study population consisted of all patients aged 0 - 14 years with retinoblastoma admitted to the pediatric oncology department between 1 January 2010 and 31 December 2019.

Inclusion criteria: Patients for whom the diagnosis of retinoblastoma was evoked on the basis of clinical and CT findings were included in the study.

Non-inclusion criteria: Children for whom the diagnosis of retinoblastoma was not sufficiently documented due to the absence of clinical information and the result of an orbito-cerebral CT scan were not included in the study.

Data were collected from a pre-test questionnaire on all the files of children with retinoblastoma during the study period. An individual collection sheet was completed for each patient, the model is reproduced in the **Appendix**.

The individual data collection form was filled in for the epidemiological variables, *i.e.* the child's identity and the socio-demographic data of both parents and their addresses. Diagnostic information included the mode and date of admission of the patient to the oncology department of the CHU-YO, the symptoms on admission and the results of paediatric and ophthalmological examinations (eye fundus). The positive diagnosis and extension were made using ultrasound, orbital-cerebral CT scan, chest X-ray, anatomopathological examination and biology (CSF, bone marrow). The therapeutic option and the means of treatment were recorded, as was the assessment of the outcome, which was based on patient survival.

The data were analysed using CS Pro software version 7.2 and SPSS French version 25. Categorical variables were compared using Pearson's Chi-square test at the 5% significance level. The overall survival rate was estimated using the Kaplan-Meier method. Graphs were constructed by means of Excel version 2013 software.

The following operational definitions have been used:

Lost to follow-up (LOS): Any patient who has completed treatment and has not been heard from for 6 weeks.

Treatment drop-out: Any patient undergoing the curative process who does not complete treatment and who is more than four weeks beyond the scheduled treatment date.

Management delay: Time between diagnosis and the first medical act per-

formed in the paediatric oncology department of the CHU-YO.

Consultation time: Time between the first sign and consultation in the paediatric oncology department of the CHU-YO.

Diagnosis delay: Time between admission to the paediatric oncology department of the CHU-YO and diagnosis.

Average socio-economic level: Civil servants and shopkeepers.

Low socio-economic level: Occupations of farmers, stockbreeders and employees.

3. Results

Epidemiological Data

The paediatric oncology department of the CHU-YO registered 1088 children with cancer during the period 2010-2019, including 219 cases of retinoblastoma, representing 20% of cancers. We selected 204 cases that met the inclusion criteria. The incidence was 20.4 cases per year, with a rate of 18% recorded in 2019, as shown in Figure 1.

We found 116 (57%) boys and 88 (43%) girls, giving a sex ratio of 1.31. The mean age was 35.06 months, with extremes of 2 months and 8 years and a standard deviation of 17.45. The 36 to 48 months' age group included 60 patients, *i.e.* 29% of cases, as shown in Table 1.

Of the 204 cases of retinoblastoma, 157 patients had the unilateral form, *i.e.* 77% of cases, and 47 patients had the bilateral form, *i.e.* 23% of cases.

The mean age at diagnosis was 26.94 months with extremes of 2 months and 60 months and a standard deviation of 14.81 for the bilateral form and the mean age for the unilateral form was 37.5 months with extremes of 2 months and 96 months and a standard deviation of 17.65 as shown in Table 1.

The center region accounted for most of the patients (27%), as shown in Table 2.

The fathers were farmers in 72% of cases, as shown in Figure 2.

Housewives represented 91% of the total workforce, as shown in Figure 3.

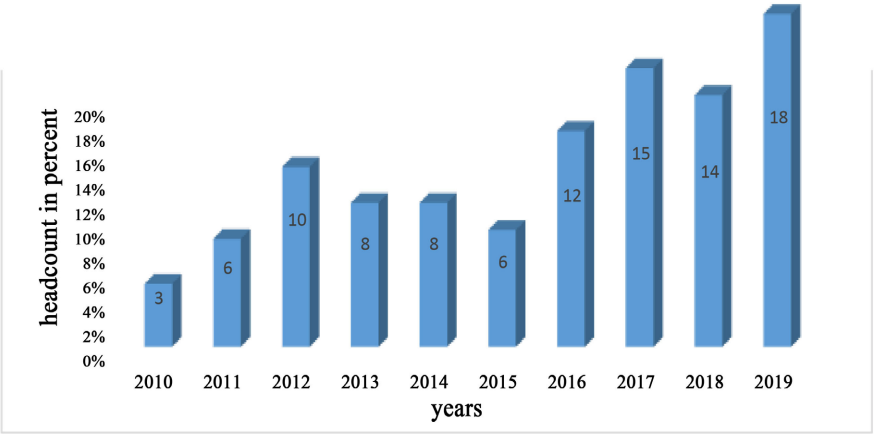

Figure 1. Distribution of patients by year of diagnosis.

Table 1. Distribution of patients according to age and laterality of the tumor.

Age group (months)	Laterality Unilateral	Bilateral	Total	
			Number	Percentage (%)
< 12	10	5	15	7
[12 - 24]	19	15	34	17
[24 - 36]	28	10	38	19
[36 - 48]	49	11	60	29
[48 - 60]	30	4	34	17
≥60	21	2	23	11
Total	**157**	**47**	**204**	100

Table 2. Distribution of patients by origin.

Origin	Number (n = 204)	Percentage (%)
Center	55	27.0
High Basin	10	4.9
East	15	7.4
North	24	11.8
Sahel	9	4.4
Mouhoun loop	8	3.9
South-west	3	1.5
East center	16	7.8
Central tray	12	5.9
North center	10	4.9
Waterfalls	6	2.9
South centrer	7	3.4
West center	15	7.4
Others	14	6.9
Total	**204**	**100**

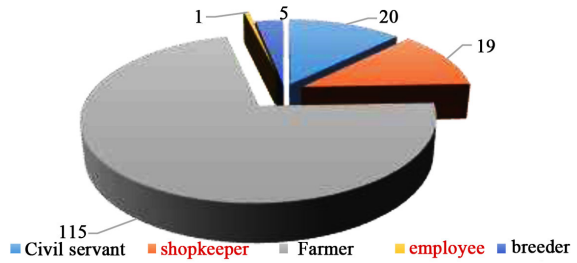

Figure 2. Distribution of patients by father's profession (n = 160).

Figure 3. Distribution of patients by mother's profession (n = 176).

Clinical Data

The first revealing sign was leukocoria, found in 147 patients (72%) (Figure 4).

The first revealing sign in the bilateral form was leukocoria, present in 28 out of 47 patients, *i.e.* a proportion of 60% (Figure 5).

The first sign of unilateral retinoblastoma was exophthalmos, found in 121 of 157 patients (77%) (Figure 6).

One hundred and twenty (120) patients had already received medical treatment (eye drops and/or antibiotics) prior to admission to the paediatric oncology department of the CHU-YO, as shown in Figure 7.

On admission to the paediatric oncology department of the CHU-YO, exophthalmos was the main symptom in 150 patients, representing 74%, as shown in Figure 8.

The time between the first sign and consultation in the paediatric department of the CHU-YO ranged from 02 days (minimum) to 46 months (maximum), with an average delay of 8.73 months in Figure 9.

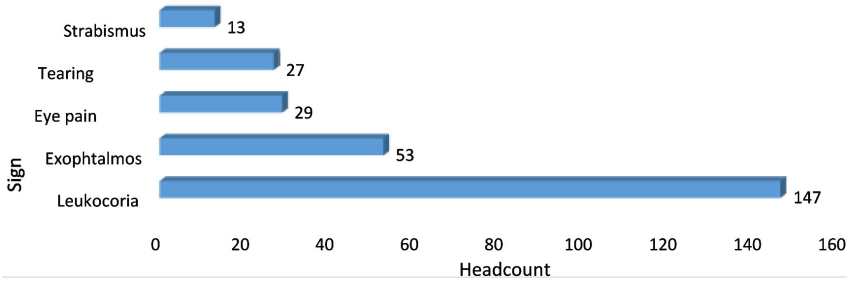

Figure 4. Distribution of all retinoblastoma patients according to first diagnostic sign.

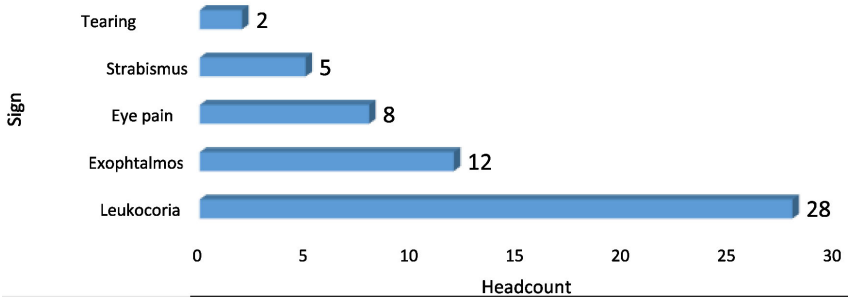

Figure 5. Distribution of tell-tale signs in bilateral retinoblastoma.

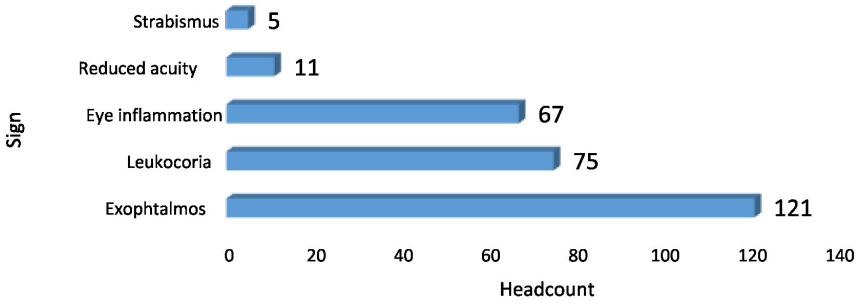

Figure 6. Distribution of tell-tale signs in unilateral retinoblastoma.

Figure 7. Distribution of patients according to first-line treatment (n = 204).

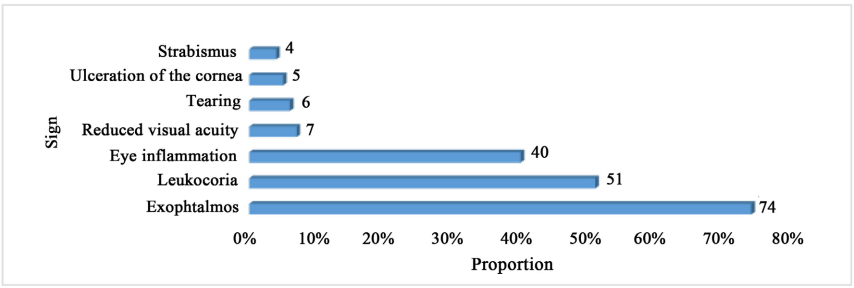

Figure 8. Distribution of patients according to symptoms on admission.

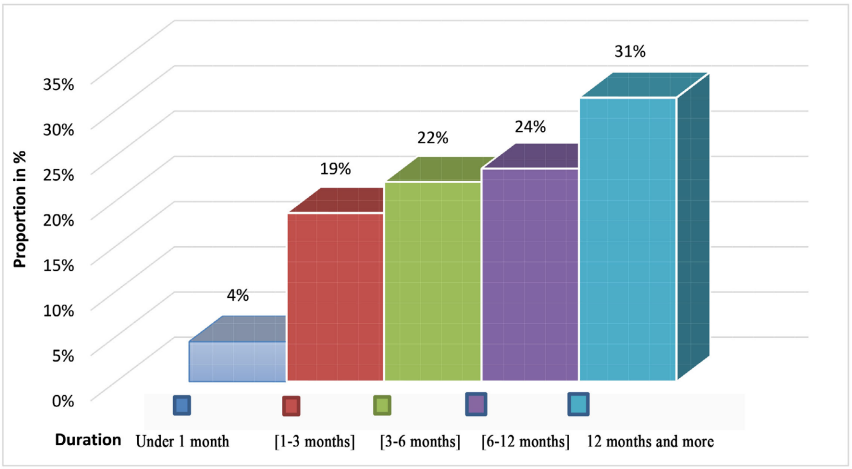

Figure 9. Distribution of patients by consultation delay (n = 204).

Ninety-eight (98) patients had metastatic disease (involvement of the brain, spinal cord, lungs, abdomen and cerebrospinal fluid).

Involvement of the cerebral parenchyma was found in 51 of the 98 patients with metastatic forms, *i.e.* a proportion of 52%; invasion of the spinal cord was found in 45 patients, *i.e.* a proportion of 46%; the cerebrospinal fluid contained atypical cells in 4 patients; the abdominal ultrasound was infiltrated in one patient and the lungs were invaded in one patient.

Retinoblastoma can be extraocular or intraocular. The extraocular form was found in 89% of patients (181 patients) and the intraocular form in 11% (23 patients).

Therapeutic Data

One hundred and two (102) patients were eligible for curative treatment as shown in Table 3.

It should be noted that for seventeen (17) patients we did not have parental consent for treatment and five (5) patients had died before the start of treatment.

As regards curative treatment, 51 patients had completed treatment and 22 had died, as shown in Table 4.

The mean time from diagnosis to the start of treatment was 18.92 days, and the longest time was 210 days, as shown in Table 5.

Evolution

Of the 51 patients who completed their treatment, 31 patients (61%) went into remission and 11 patients died, as shown in Figure 10.

Table 3. Distribution of patients by type of treatment.

Treatment type	Headcount (n = 182)	Percentage (%)
Curative	102	56
Palliative	80	44
Total	**182**	**100**

Table 4. Distribution of patients according to follow-up of curative treatment.

Curative treatment	Headcount (n = 102)	Percentage (%)
Cure completed	51	50
Abandon	29	28
Deaths	22	22
Total	**102**	**100**

Table 5. Distribution of patients by length of time in care.

Duration (day)	headcount	Percentage (%)
<5	41	24
[5 - 10]	53	31
[10 - 15]	22	13
[15 - 30]	26	15
≥ 30	29	17
Total	**171**	**100**

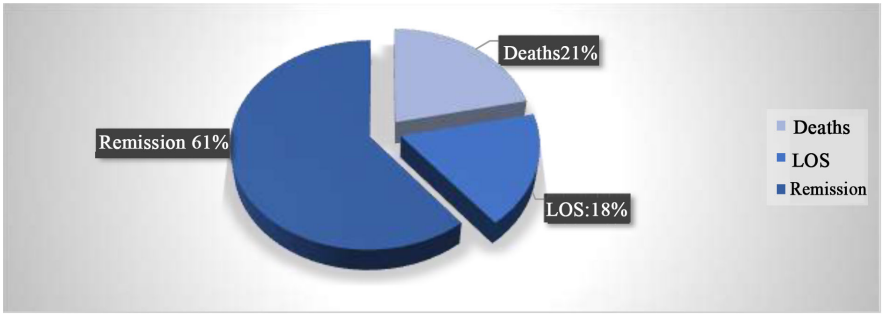

Figure 10. Outcome of patients who completed non-conservative treatment (n = 51).

Of the 51 patients who underwent enucleation, 38 benefited from ocular prostheses.

Of the 80 patients undergoing palliative treatment, 57% died, as shown in Figure 11.

Eighteen percent (18%) of patients were alive, as shown in Table 6.

The overall survival rate was 32%.

Linking Letality to Epidemiological and Clinical Data

There was no association between age, sex, socio-economic level or laterality of the disease and lethality. There was no association between the delay in consultation and lethality also (Table 7). However, there was a link between the extent of the tumor and lethality (Table 8).

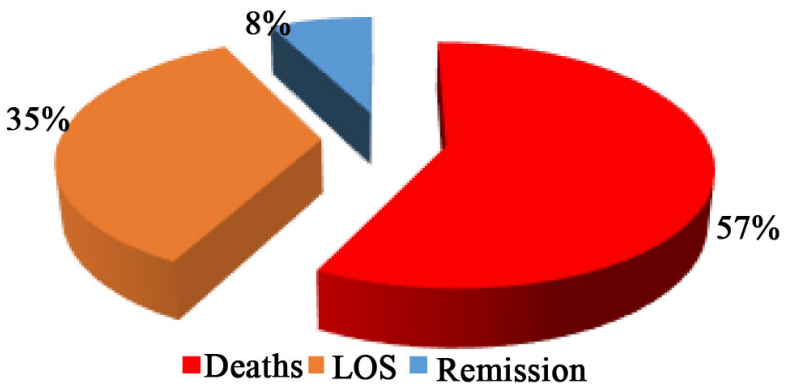

Figure 11. Distribution by outcome of patients who started palliative treatment (n = 80).

Table 6. Distribution of patients by outcome.

Evolution	headcount	Percentage (%)
Deaths	84	41
Abandon	46	23
Living	37	18
LOS	37	18
Total	**204**	**100**

Table 7. Distribution of consultation time in relation to lethality.

Consultation deadlines (months)	Dead	Lethality Not dead	Total
<1	4	5	9
[1 - 3]	17	21	38
[3 - 6]	19	26	45
[6 - 12]	19	29	48
≥12	25	39	64
Total	**84**	**120**	**204**

Khi-deux of Pearson = 0.42725016; p-value = 0.98018567.

Table 8. Distribution of lethality according to tumor extension.

	Tumor extension			
Lethality	Metastatic forms	Localised forms with optic nerve	Localised forms without optic nerve	**Total**
Dead	52	19	13	84
Not dead	46	33	41	120
Total	**98**	**52**	**54**	**204**

Khi-deux = 12.698, p-value = 0.002.

4. Discussion

Our study was a descriptive and analytical cross-sectional study.

Retinoblastoma is the most common intraocular tumor in children [12] [13] [14] [15], with approximately 7000 cases each year worldwide, including at least 2000 cases in Africa.

In our study, the annual distribution of retinoblastoma showed a progressive increase in the number of new cases over the years. A total of 204 cases were recorded during the study period. While there were only 7 patients in 2010, this figure has risen to 37 patients in 2019, with an average of 20.4 cases per year.

Our results are better than those of the series by C. Dial et al, who found an annual recruitment of 10.6 cases in Senegal [16].

This difference could be explained by the fact that the paediatric oncology department of the CHU-YO is the only center for the management of retinoblastoma in Burkina Faso, unlike other countries which have several management centers.

In the literature, the mean age at diagnosis of retinoblastoma was 2 years for unilateral forms and 1 year for bilateral forms [17].

In our study, the mean age at diagnosis for bilateral forms was 26.94 months and 37.50 months for unilateral forms. The mean age for the entire study population was 35.06 months, with extremes of 02 months and 08 years. Among patients in the study by Sadik Taju Sherief *et al.* in Ethiopia [18] the mean age at presentation was 34 months in unilateral cases and 19.5 months in bilateral cases.

Our results are comparable to those of Sankara [9] who found a mean age of 33 months with extremes of 1 month and 96 months.

These results reflect the tendency for retinoblastoma to be diagnosed late in low-income countries where the median age was 30.5 months compared with 14.1 months in high-income countries in the Global Retinoblastoma Study Group [10].

These results could be explained by the African context of these studies, which was marked by delays in consultations, inadequate promotion of screening for the disease, and the distance between health facilities and residential areas. In Western countries, the disease is diagnosed much earlier, thanks to public aware-

ness campaigns run by retinoblastoma associations and the availability of appropriate technical facilities. In Türkiye, the average age for the population as a whole is 25 months [19]. A French study found an average age of 27 months [20]. In the United States, the average age at diagnosis was 24 months for the population as a whole [21]. In China, Zhao found a mean age of 23 months for the population as a whole [22].

The majority of authors report that both sexes are affected, with a predominance of males. In Finland, Kalle *et al.* in their study of 205 cases reported a sex ratio of 1.34 [23]. In contrast, the study by Kagmeni *et al.* in Cameroon found a female predominance with a sex ratio of 0.42 [24].

In our study, our data are in line with the literature, with a predominance of male involvement and a sex ratio of 1.31.

In the literature, approximately 1/3 of retinoblastomas are located bilaterally compared with approximately 2/3 unilaterally. In our study, 23% of cases were bilateral and 77% unilateral.

Our data are in line with the literature, in particular the series published by Mac Carthy (USA) in which the unilateral form was present in 70% of cases and the bilateral form in 30% [25]. In the study conducted by Chebbi in Tunisia, the unilateral form was present in 69% of cases and the bilateral form represented 31% of cases [26]. In the study conducted by Sow *et al.* in Senegal, the unilateral form was present in 79.66% of cases and the bilateral form in 20.34% [27]. In Ethiopia in 2022, Sadik Taju Sherief *et al.* [18] found 84.3% of cases to be unilateral and 15.7% bilateral. This could be explained by the hereditary nature of the bilateral form.

The two clinical signs of retinoblastoma are leukocoria and strabismus. But in low-income countries, buphthalmia or exophthalmia are often found because of delays in consultation.

Various clinical manifestations were observed in our study at the time of diagnosis, but the most frequent were leukocoria, present in 72% of cases, followed by exophthalmos (26%) and strabismus (6%).

Our results are similar to those of African series Sankara [9] in Burkina Faso in 2020 found 31.25% leucocoria and 59.37% exophthalmos; in Morocco Elketanni *et al.* found 69% leucocoria and 47% exophthalmos [27]; Kagmeni *et al.* in Cameroon found leucocoria in 67.2% of cases and strabismus in 8.7% [24].

Globally, the most frequent indication for referral was leukocoria (62.8%), followed by strabismus (10.2%) and proptosis (7.4%) according to the multicenter Global Retinoblastoma Study Group [10].

Ocular redness, ocular pain and reduced visual acuity were the least frequent functional signs [28]. Our results could be explained by the fact that the disease was diagnosed at an advanced stage.

According to many authors, the delay in consultation after the appearance of the first warning sign reflects the quality of the country's medical culture and the parents' level of awareness [28] [29]. This delay conditions the visual, aesthetic and above all vital prognosis of the disease [29].

According to Palazzi, the risk of enucleation increases by 5% for each month of delay [30]. For Butros, the risk of metastasis increases significantly after a delay of 5 to 6 months [31]. According to Dimaras, a delay of 6 months implied a mortality rate of 70% [32].

In our study, the time between the appearance of the first sign and consultation at the CHU-YO varied between 02 days and 46 months, with an average of 8.73 months. Our results differ from those of emerging and developed countries. Salistre in Brazil in 2016 had, an average of 5.4 months [33] and Lin in Canada (2009), 21 days [34]. The best example was Canada, with an average consultation time of 2.8 weeks [35].

This long delay in consultation in our context could be attributable to a lack of awareness of the disease among the general public.

Retinoblastoma may be extraocular or intraocular. In African series, Kaka *et al.* in Niger found a predominance of extraocular forms in 94.6% and 5.4% for the intraocular form [36]; in the DRC, Wakamb *et al.* in their series found 91.7% extraocular retinoblastoma and 8.3% intraocular retinoblastoma in 2013 [37]. Robert M *et al.* found 76% extraocular retinoblastoma in their 2018 series from Côte d'Ivoire and Democratic of the Congo [38].

In our series, extra-ocular forms accounted for 89% of patients and intra-ocular forms for 11%. These extraocular forms, which are very common in developing countries, can be explained by the delay in diagnosis. There is a lack of awareness of the disease among the general public, and even among some health workers. Added to this are the difficulties of geographical and financial access to the pediatric oncology department of the CHU YO, which is the only retinoblastoma department in the country. In developed countries, diagnosis is made at the early intraocular stage [10] [39].

In the literature, 3 (three) therapeutic options are presented for the treatment of retinoblastoma: conservative treatment, non-conservative treatment and palliative treatment. In our current context in Burkina Faso, 2 (two) types of treatment are possible: non-conservative treatment and palliative treatment in case of optic nerve and/or cerebral parenchyma involvement. In our study, 182 patients agreed to undergo treatment, of whom 56% underwent curative non-conservative treatment and 44% palliative treatment. Seventeen (17) others had parents who were opposed to treatment and 5 patients had died before the start of treatment.

Non-conservative treatment consists of preoperative chemotherapy (neo-adjuvant) followed by enucleation surgery and then postoperative chemotherapy (adjuvant) according to the GFAOP protocol applied in the department [9].

In our study, of the 102 patients who started curative treatment, 50% completed the treatment, 28% abandoned the treatment and 22% died during treatment. In the study conducted by Kagmeni *et al.* [24] in Cameroon, surgery was the only treatment option.

In the literature, in the series by Choi *et al.* in Korea, 33% of patients received non-conservative treatment [40]; Sow *et al.* in Senegal reported over 95%

non-conservative treatment [27]. Chemotherapy has revolutionized the management of retinoblastoma in our country. Indeed, prior to 2006, patients were treated mainly by surgery (enucleation or exenteration); chemotherapy was exceptional, and used postoperatively [41].

Gombos reported that the probability of a retinoblastoma responding to initial chemotherapy is higher if the tumor is located in the macula and if the patient is more than 2 months old. Tumors less than 2 (two) mm in diameter may be less responsive to this treatment [42].

Chemotherapy is very burdensome for most patients because it has a large number of side effects. In our patients, the main side-effects we observed were recurrent infections due to neutropenia, digestive problems and mucositis.

Monitoring was carried out monthly, quarterly, six-monthly and then annually in conjunction with the ophthalmologists. Monitoring included a clinical examination.

Of the 51 patients who completed the cure with non-conservative treatment, 38 patients received prostheses, a rate of 74.5%.

We recorded a loss of 37% of patients. Our results differ from those of Traoré in Mali in 2013, who reported a 20% attrition rate [15]; Kagmeni *et al.* found an exceptional rate of 74.5% in Cameroon [24].

Our results could be explained by the socio-cultural constraints of the population, who do not understand the disease, which they often associate with religious, mystical and socio-cultural manifestations. For example, enucleation is often poorly accepted by some parents. Seventeen (17) patients did not receive parental consent for treatment, and five (5) died before treatment was started. Parents do not understand the importance of follow-up and lack the financial means to keep appointments. In our study, cases considered as treatment abandonment represented advanced-stage tumors.

In fact, the average time between diagnosis and the start of treatment was 18.92 days, with the longest delay being 210 days.

Metastatic forms accounted for 48% and localised forms with optic nerve involvement 25%. These forms explain the high death rate.

The death rate in our series was 41%. Kaka *et al.* in Niger found 75% deaths in 2016 [36]. In Congo, Kazadi [43] in 2012 found a mortality rate of 92.5% in a study carried out at Kinshasa hospital over a 20-year period. This mortality rate is virtually nil in industrialised countries. The best example is Canada, with a death rate of less than 1% [35]. Worldwide mortality due to this cancer is around 5-11%. However, this rate rises to 40% - 70% in developing countries because of delays in diagnosis [44] [45].

In our study, there was not a statistically significant relationship between consultation delay and lethality. However, several studies have shown that mortality is very high for late consultation [31] [32] [33]. Indeed, late consultation exposes patients to the risk of metastasis and limits their therapeutic options.

Our overall survival rate was 32%. Dial C *et al.* found a 5-year survival rate of

70% [16].

While the overall survival rate in developed countries such as the USA and Canada is almost 100%, the overall survival rate in African countries is still low [46].

The availability of a variety of suitable treatments, including intravenous, intra-arterial and intravitreal chemotherapy in addition to enucleation, could not only improve patient survival but also save their vision, especially in bilateral forms [47].

There was a statistically significant association between tumor extension and lethality. The more extensive the tumor, the greater the probability of losing one's life as a result of the disease in our patients, multiplied by 0.288.

Over the last ten years, several studies have investigated the histoprognostic factors influencing recurrence and death in patients with retinoblastoma. Involvement of the optic nerve transection slice is considered by Kopelman *et al.* to be a microscopic metastasis [48]. It is a poor prognostic factor favouring death. For Cuenca *et al.*, extra-scleral extension is a marker of severity with a high potential for systemic extension and death [49]. These conclusions corroborate our results.

The late consultation (mean 8.73 months) and the high number of metastatic forms with or without optic nerve involvement would explain the high mortality and low survival rate in our context. The absence of intra-arterial and intravitreal chemotherapy could also explain the high mortality rate.

Furthermore, the functional prognosis of retinoblastoma remains anecdotal due to the advanced forms and the absence of conservative treatment such as transpupillary thermotherapy.

The limitations of our study were due to the fact that some files were incomplete. We therefore retained 204 cases because certain additional examinations were not found, as were certain files.

5. Conclusions

Retinoblastoma is a highly malignant neuroepithelial tumor of infants and young children. Knowledge of the genetic mechanisms and, above all, recognition of the early clinical signs of retinoblastoma will enable us to anticipate the occurrence and fateful evolution of this cancer.

To meet this challenge, we need to promote the use of the Buckner test by healthcare professionals every time they come into contact with children aged between 0 and 5, and step up public education on the importance of examining children's eyes for leukocoria and strabismus.

Recommendation for Health Workers

Refer children with leukocoria and/or strabismus to referral structures early.

Inform parents more about the need for regular and permanent monitoring for conclusive results of care.

Recommendation to Policy Makers

It is recommended to equip and increase the number of retinoblastoma treatment centers with qualified human resources.

Conflicts of Interest

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

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Appendix

Collection form

Number... Year 20...

I-Social and demographic data

1-Children

- Date of birth: ..... DD/MM/YYYY
- Age at diagnosis: ..... (months)
- Sex: ..... 1 = boy 2 = girl
- School attendance: .... 1 = yes 2 = no
- Region of origin: 1-Center; 2-High-Basins; 3-East; 4-North ; 5-Sahel; 6-central tray; 7-South-West; 8-east center; 9-Mouhoun loop; 10-Nord center; 11-Waterfalls; 12-South center; 13-West center; 14-Others
- Province of origin: .....

2-Parents

2-1: Father

- Age: ...
- Profession: 1 = civil servant; 2 = shopkeepers; 3 = farmer; 4 = employee; 5 = breeder; 6 = others

2-2: Mother

- Age: ...
- Profession: ..... 1 = Housewives; 2 = Trader or shopkeepers; 3 = civil servant; 4 = others

II-Diagnosis

1-Clinical

- Date of admission: ..... DD/MM/YYYY
- Mode of admission:

✓ 1 = Direct
✓ 2 = Referred
✓ 3 = Transferred (Name of the structure……. Reason for referral.....)

- First symptoms noticed by parents: .....

✓ 1 = Leukocoria
✓ 2 = Strabismus
✓ 3 = Exophthalmia
✓ 4 = Others: .....

- Time from 1st symptom to admission (in months): .....
- Main symptoms on admission

✓ Leukocoria: .... 1 = yes 2 = no
✓ Strabismus: ..... 1 = yes 2 = no
✓ Exophthalmos: ..... 1 = yes 2 = no
✓ Decreased visual acuity: .... 1 = yes 2 = no
✓ Ocular inflammation: ..... 1 = yes 2 = no
✓ Impairment of general condition: ..... 1 = yes 2 = no
✓ Other signs: .... 1 = yes 2 = no

(Cite.....)

- Ophthalmological examination..... 1 = yes 2 = no
- Affected side: 1 = Left 2 = Right 3 = Bilateral
- Eye fundus: … 1 = yes 2 = no

Comment: .....

.....

- Classification 1 = yes 2 = no

2-Para clinical

A. Imaging

- Ocular echo: ..... 1 = yes 2 = no

Comment..... .....

- Oculocerebral CT scan..... 1 = yes 2 = no

✓ Tumour size: .....

✓ a = calcifications

✓ b = Optic nerve involvement

✓ c = Intra conical fat invasion

✓ d = Invasion of the oculomotor muscles

✓ e = Cerebral parenchyma involvement

- Medullogram:... 1 = yes 2 = no

✓ a = Normal b = Infiltrated

- Cerebrospinal fluid analysis..... 1 = yes 2 = no

✓ a = normal b = infiltrated

- Chest x-ray..... 1 = yes 2 = no

✓ a = normal b = abnormal

- Abdo echo..... 1 = yes 2 = no

✓ a = normal b = abnormal

- HIV ..... 1 = yes 2 = no

✓ a = Positive b = negative

- Anatomopathology..... 1 = yes 2 = no Date of tests: ....

B. Classification

- 1 = REESE stage: GI:... GII:... GIII:... GIV:..... GV:..... or
- 2 = International classification (ABC): A:... B:.... C:.... D:..... E:....
- Secondary locations ..... = yes 2 = no a-cerebral b-osseous c-meningeal d-pulmonary e-medullary f-other

III-Therapy

- Start date.....
- Non-conservative treatment: .....

1 = enucleation only; 2 = enucleation followed by chemotherapy; 3 = neoadjuvant chemotherapy; 4 = enucleation chemotherapy plus radiotherapy 5 = other to be specified .....

- Conservative treatment: .....1 = yes 2 = no If yes, specify .....
- Cure completed….. 1 = yes 2 = no

✓ (if yes, date treatment completed:.....)

✓ (if no Reason: a = Died b = abandoned)

IV-Evolution

1. At 6 months from the start of treatment

Date:..... DD/MM/YYYY

- Alive:... 1 = yes 2 = no
- Remission:.... 1 = yes 2 = no
- Recurrence:... 1 = yes 2 = no
- (a = Same eye b = Contralateral eye) date:……..
- Change in general condition:.... 1 = yes 2 = no

Death:... 1 = yes 2 = no (Date:.... Reason:.....)

2. Latest available date..... .

- Latest status

✓ Alive :.... 1 = yes 2 = no

- Recurrence:... 1 = yes 2 = no

✓ (a = Same eye b = Contralateral eye) date:.....

- Survival since diagnosis :

✓ Date of diagnosis:.....

✓ Date of last news.....

Death:... 1 = yes 2 = no (Date:.... Reason:.....)