

LIFE COURSE AND DELAY IN ONCOPEDIATRICS REMEDY: case of Burkitt's lymphoma in Abidjan (Côte d'Ivoire)

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ABSTRACT : In Côte d'Ivoire, cancer pathology in children is on the rise. Until 2007, the total number was 556 cases (Effi, A.B. et al., 2012). From 2007 to 2015, the number of cases is 863 with 85.3% of Burkitt's lymphoma (L. Couitchéré et al., 2019). However, the remission rate at the Pediatric Oncology Unit of the Treichville University Hospital is 30% (A. J.-J. Yao, L. Couitchéré et al., 2010). Faced with this public health problem, this study reveals that families experience delays in accessing the Pediatric Oncology Unit during the child care itinerary. In order to understand this phenomenon, socio-anthropological approaches question the diachronic and synchronic aspects of care in various researches. The perspective of the approach, that of the life course, is an innovation in the works of in oncopediatrics in Côte d'Ivoire because it combines these different aspects in the same study. To this end, 56 families affiliated with the Pediatric Oncology Unit of the Treichville University Hospital obtained by "snowball" whose "grain" is made up from patient files, submitted themselves to a life calendar grid and to an interview guide. The information collected was processed with the TRAMINER module of the R statistical software. From this analysis, it emerges that there is an institutionalization of the renunciation of care. This institutionalization is a consequence of the institutionalization of the life course of families. However, there is a diversification in the courses, as they are not completely homogeneous. This contribution is an aid to the construction of a program to reduce infant mortality due to Burkitt's lymphoma in Côte d'Ivoire.

KEYWORDS: Life course - pediatric burkitt lymphoma – institutionalization – delay in seeking care-Abidjan- Côte d'Ivoire

I. INTRODUCTION

In Côte d'Ivoire, pediatric cancer is starting to take off. Until 2007, the total number of cases was 556 (Effi, A.B. et al. 2012). From 2007 to 2015, the number of new cases reached 863 with a predominance (85.3%) of Burkitt's lymphoma (L. Couitchéré et al., 2019). In addition, within two years (2016 to 2017), the number of new cases recorded is 338, which represents only 10 to 15% of cancer cases having had recourse to the Pediatric Oncology Unit of the Treichville University Hospital Center (CHU) (According to the Franco-African Pediatric Oncology Group (GFAOP), 2016; 2017; 2018). This center is the reference point for cancer treatment in Côte d'Ivoire.

The death rate in the Pediatric Oncology Unit is 70%, attributable to late diagnosis because Burkitt's lymphoma in children is chemosensitive (J.-J. Yao Atteby et al., 2010). The late diagnosis observed by the doctors is the product of a delay in recourse of the families of sick children to the Unit. The delay in accessing health services is identified as a non-use of health services and professionals despite health "disorders" that constitute a renunciation of care (C. Desprès, 2013). This update discloses a problem of renunciation of care by families. Thus, this article seeks to explain the renunciation of care by families of children with Burkitt's lymphoma before diagnosis.

This interest in the determinants of the renunciation of care is not new. Indeed, the democratization of care contributes to non-recourse because it generates relationships of leadership, mistrust and conflict, which is coupled with a dysfunction of the health system (Z. A. K. Dayoro and G. B. E. Tié, 2016).

The perception of Burkitt's lymphoma addresses the aspect of the appreciation of the severity of the disease by families (T. MambuNyangi Mondo et al., 2010). This appreciation leads to a social pressure which translates the ignorance of the Burkitt's lymphoma through the gradual recourse. This graduation begins with self-medication, and then leads to the most financially and geographically accessible therapist (B. M. Yoro, 2012). Also, financial constraints are reported as a major obstacle due to the economic resources of families (M. E. Mafuta and P. K. Kayembe, 2011). This obstacle favors an arbitration of recourse which directs towards traditional treatments (M. Touré et al., 2013). Concerning cancers, ignorance is put in the foreground.

Traditional therapists guide the search for care, according to their knowledge base and thus assimilate the symptoms to other diseases (C. Baxerres and J.Y. Le Hesran, 2004). Similarly, the lack of knowledge of cancers by healthcare personnel (general practitioners, nurses and midwives) constitutes a barrier to the referral of patients to the reference center (S. Aloulou et al., 2006).

Moreover, these approaches, taken individually, do not reflect the dynamics of the interaction that leads to social inequalities in health. These inequalities are revealed by the delays in recourse questioned through the renunciation of care. Therefore, this article proposes an analysis from the perspective of the life course theory. This perspective questions the different dimensions (in particular the course of care, the family course, the residential course and the education-professional course) of life in its relation to the renunciation of care for pediatric Burkitt's lymphoma.

II. METHODOLOGY

The "snowball" technique was used to construct a sample of 58 individuals. These individuals are parents of families of children with Burkitt's lymphoma between 2014 and 2018 and affiliated with the oncology unit of the pediatric department of the Treichville University Hospital. The interviews took place in the second half of 2018. The meetings took place in the homes of the families (17 out of 58) and within the pediatric department (41 out of 58). Depending on whether or not the families continue biomedical care at the Treichville University Hospital.

A life calendar grid was administered to family members of children with Burkitt's lymphoma. This tool can be used in a quantitative approach (A. Gherghel and M.-C. Saint-Jacques, 2013). It is a table whose columns make it possible to retrace the transitions of life trajectories. The tool is associated with a guide for reconstructing courses in family, educational, residential, professional and care trajectories.

A quantitative approach is used to analyze the data. Probabilistic analysis (statistical analysis) is associated with a snowball technique (G. Benoît, 2009). The process starts with the reading of the interviews, the coding then, the entry and finally, the processing with the library or the package TraMineR 2.0.8 (Trajectories Miner in R) of the R 3.5 software. This analysis is used to achieve a classification of the different courses, a distribution with a Pearson Chi-square interdependence test

III. RESULTS

3.1 Distribution according to the Murphy classification

Table 1 : Stage frequency

	VA	VR
Stage 1	3	5,2%
Stage 2	7	12,1%
Stage 3	35	60,3%
Stage 4	13	22,4%

Source : DAYORO Arnaud KOUASSI Tanoh ,AHUIE Assian Agnes Chantal, 2018

Murphy identifies four (4) stages in the progression of cancer. Stages 1 and 2 are less advanced than stages 3 and 4.

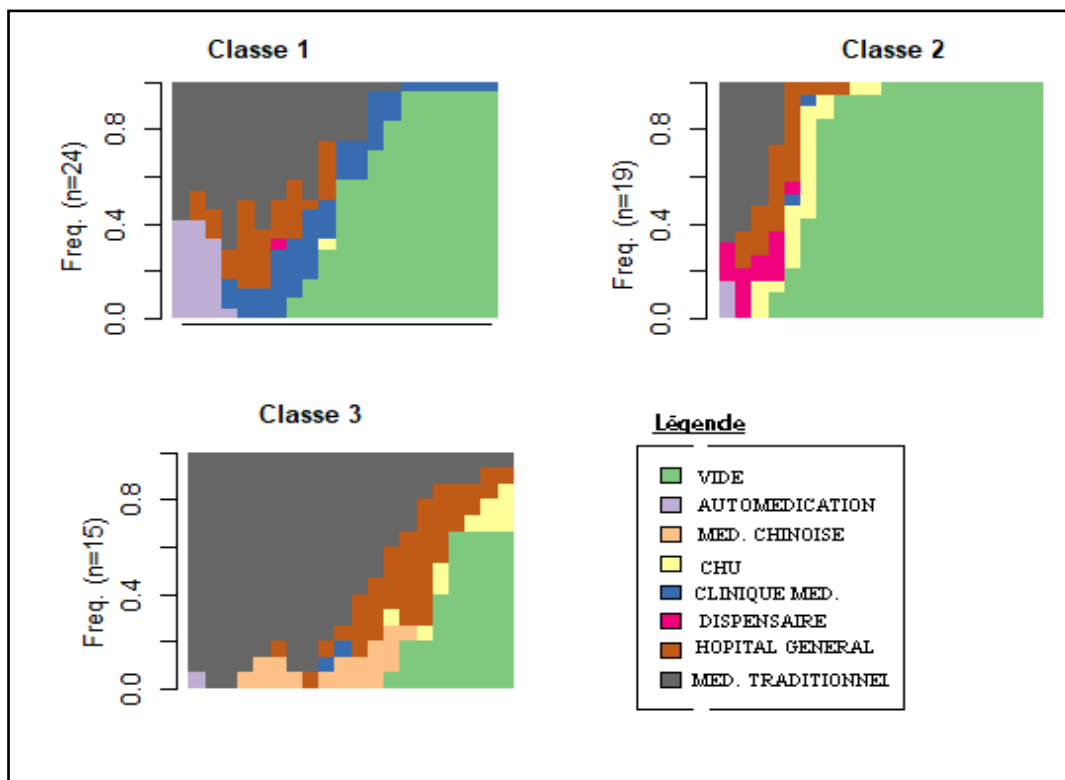
Table 1 shows that the cumulative number of individuals in stages 1 and 2 is 10 out of 58, or 17.3%. However, stage 1 and stage 2 represent early stages of Burkitt's lymphoma.

Stage 3 includes the largest number of individuals, 35 out of 58, or 60.3%. This stage corresponds to an advanced stage of the disease. But, the most advanced form is at stage 4. It has a larger number (13 out of 58) than the early stage (10 out of 58).

3.2 Healthcare pathway

The different care trajectories have been classified according to three typologies (figure 1). The typologies are not homogeneous, but they all have an important transition to traditional African medicine. However, it is possible to distinguish in class 1, a predominance of transitions to traditional African medicine, the medical clinic, to the general hospital and to self-medication.

Picture 1 : Classification of Healthcare pathways



This class is the *Trad-Cli-HG-Auto* class. Class 2 has the shortest transition to traditional African medicine followed by transitions to the CHU (all the CHUs except the CHU of Treichville), the general hospital and the dispensary. This class is named *Trad-CHU-HG-dis*. Similarly, class 3 shows a greater transition to traditional African medicine and the general hospital, associated with the transition to Chinese medicine and the CHU: the *Trad-HG-Chin-CHU* class. In this class 3, the transition to traditional African medicine is high and the most important of the classes.

Table 2: Typology of healthcare by stage

	Stage 1	Stage 2	Stage 3	Stage 4	<p>Khi-2 de Pearson: $X=7,1686$, $ddl=6$, $p\text{-value}=0,3055$</p>
Auto-dis-Trad-Chin	0%	12,5%	62,5%	25%	
Auto-Trad-Cli-HG-dis	5,3%	5,3%	57,9%	31,6%	
Auto-Trad-CHU-Cli	13,3%	20%	60%	6,7%	

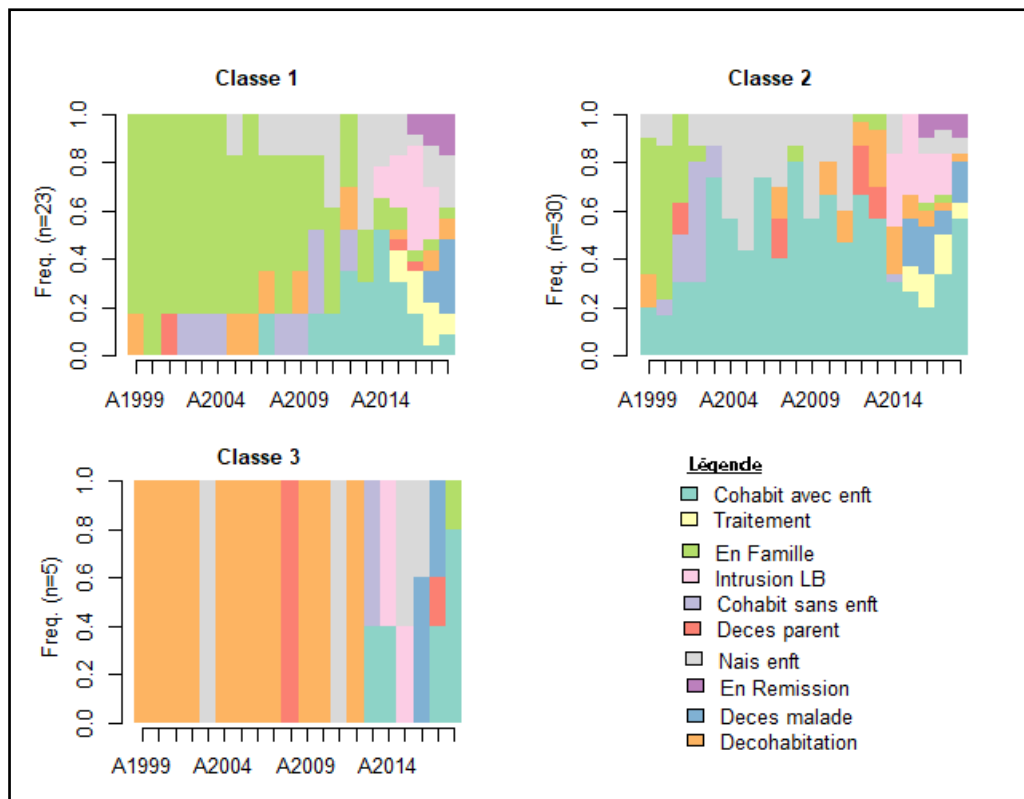
Source : DAYORO Arnaud KOUASSI Tanoh ,AHUIE AssianAgnes Chantal, 2018

This table 2 shows that the different healthcare pathways lead to late diagnosis. Indeed, the diagnoses present rates of more than 60% for stages 3 and 4. In addition, the interdependence test establishes a relationship between the pathways and the stage of the diagnoses, even if it is not significant.

3.2 family backgrounds

The different family backgrounds highlight three classes (Figure 2). Each class presents individuals in different situations. However, there is intra-class heterogeneity. Class 1 (family life) is made up of individuals who live with their family, that is to say with a parent (father, mother, brother, sister).

Picture 2 : Classification of family backgrounds



Source : DAYORO Arnaud KOUASSI Tanoh ,AHUIE AssianAgnes Chantal, 2018

As for class 2 (life as a couple), it includes individuals who lead a life as a couple before the diagnosis of pediatric Burkitt's lymphoma in their life course. Class 3 (in cohabitation) includes individuals who have experienced cohabitation in the family history.

Table 3: Family typologies by stage

	Stage 1	Stage 2	Stage 3	Stage 4	<i>Khi-2 de Pearson:</i> X= 3,776, ddl=6, p-valeur=0,707
Family life	6,7%	13,3%	56,7%	23,3%	
Married life	4,3%	13%	56,5%	26,1%	
Living apart	0%	0%	100%	0%	

Source : DAYORO Arnaud KOUASSI Tanoh ,AHUIE AssianAgnes Chantal, 2018

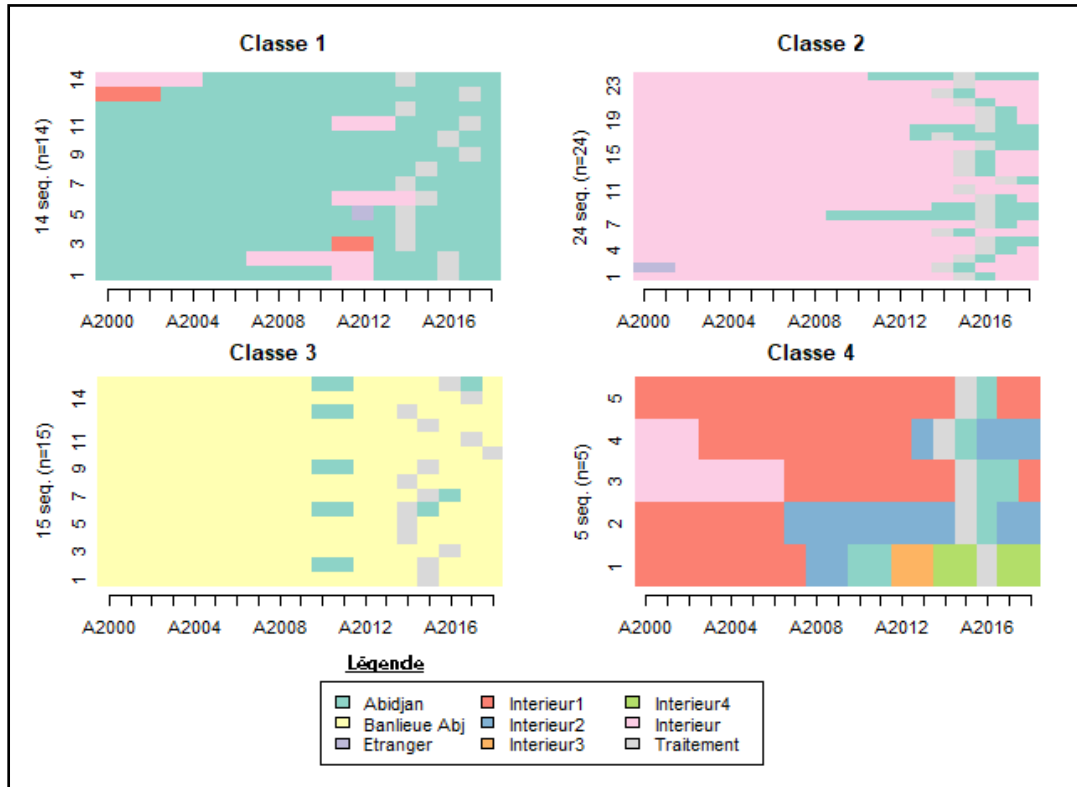
“Family life”, “couple life” and “separate living” individuals have recourse to late diagnosis. Individuals "in cohabitation" all have a late diagnosis (stage 3: 100%) while individuals "in family" record the highest rate of early diagnosis with at stage 1: 6.7% and at stage 2: 13.3%. They are followed by individuals “in couple”.

However, these individuals “in couple” have a higher rate of late diagnosis. Pearson's Chi-square test establishes a relationship between family background and stage of diagnosis. However, this relationship is not significant to conclude to an interdependence.

3.4 Residential courses

Figure 3 highlights 4 types of classes in residential courses. Class 1 (Abidjan) includes individuals whose career is dominated by the Abidjan transition. Class 2 (inland) counts individuals who lived in the interior of the country before the intrusion of Burkitt's lymphoma.

Picture 3 : Classification of residential courses



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In addition, class 3 (Abidjan suburbs) consists of individuals living in the suburbs of Abidjan before the diagnosis. And, the class (mobility) brings together individuals who have experienced significant mobility between municipalities in the years preceding the intrusion of Burkitt's lymphoma in their family life course. However, the classes are not completely homogeneous.

Table 4: Residential typologies by stage

	Stage 1	Stage 2	Stage 3	Stage 4	<p>Khi-2 de Pearson: X=6,3623, ddl=9, p-valeur=0,7032</p>
Abidjan	7,1%	14,3%	57,1%	7,1%	
Inland	8,3%	8,3%	50%	8,3%	
Suburban-Abidjan	0%	13,3%	73,3%	0%	
Mobility	0%	20%	80%	0%	

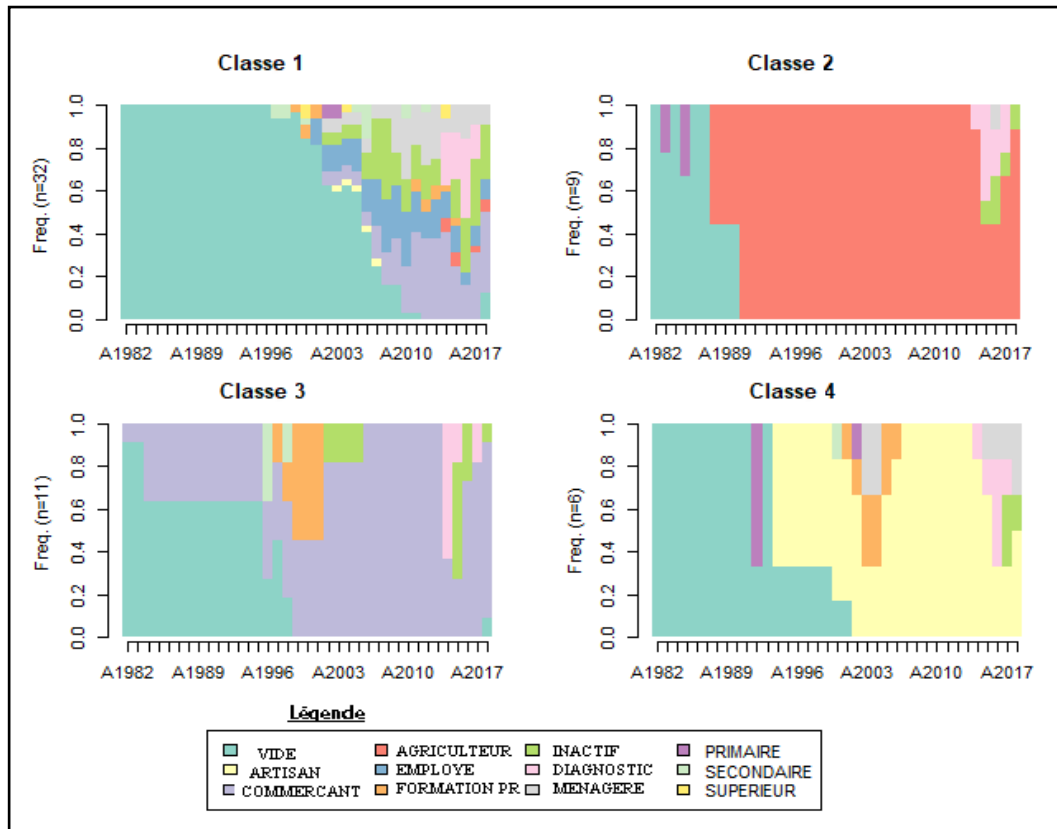
Source : DAYORO Arnaud KOUASSI Tanoh ,AHUIE AssianAgnes Chantal, 2018

Individuals a priori all have a late diagnosis. However, individuals from “Abidjan” have the highest cumulative rate of early stage (21.4%) (stage1: 7.1% and stage2: 14.3%). As for “inland” individuals, the highest advanced diagnosis rate (8.3%) for stage 4. While they have a late diagnosis rate, the lowest with a stage 3 of 50%. Individuals from the “suburban-Abidjan” have the lowest rate of early diagnosis (stage 2: 13.3%). Similarly, “mobility” individuals record the highest rate of late diagnosis (stage 3: 80%) of residential courses. Pearson's Chi-square test establishes a relationship between the residential course and the stage of diagnosis. But, this relationship cannot be used to claim interdependence.

3.5 Education-Profession Pathways

The analysis of the “educational-professional” paths makes it possible to identify 4 types of class (Picture 4 below). First, class 1 (composite) is made up of individuals who have reached secondary school or higher. It includes together individuals who were inactive, housewives, employees and traders, before the intrusion of Burkitt's lymphoma in their family life course.

Picture 4: Classification of educational-professional pathways



Source : DAYORO Arnaud KOUASSI Tanoh ,AHUIE AssianAgnes Chantal, 2018

Then, class 2 (farmer) brings together individuals who are planters in the years preceding the intrusion of Burkitt's lymphoma in their life course. They have a primary level of education or have none. In addition, class 3 (trader) is made up of individuals who have lived these years as traders. They have a secondary education and/or have completed vocational training. Finally, class 4 (craftsman) contains individuals who have undergone vocational training after primary school. These individuals occupy the profession of craftsman, before the intrusion of the Burkitt's lymphoma in their course of life. Like the classes in the other paths, the classes are not as homogeneous.

Table 5: Occupational typologies by stage

	Stage 1	Stage 2	Stage 3	Stage 4	<p>Khi-2 de Pearson: X=4,9036, ddl=9, p-valeur=0,8426</p>
Composite	6,2%	15,6%	59,4%	18,8%	
Farmer	0%	0%	66,7%	33,3%	
Trader	9,1%	18,2%	54,5%	18,2%	
Craftsman	0%	0%	66,7%	33,3%	

Source : DAYORO Arnaud KOUASSI Tanoh ,AHUIE AssianAgnes Chantal, 2018

“Farmer” and “artisan” categories of individuals do not have a single case of early diagnosis. They have the highest rates of late diagnosis with a rate of 66.3% at stage 3 and a rate of 33.3% for stage 4. In addition, “composite” individuals have a higher stage3. On the other hand, “trader” individuals have the highest diagnosis

rate with a cumulative rate of 17.3% (stage 1: 9.1 and stage 2: 18.2%). These individuals also have few very advanced diagnoses (stage 4: 18.2%) in this course. However, this latter rate is lower than the rate of 18.8% of individuals diagnosed at stage 4 among “composite” individuals. In addition to stage 4, the rate of stage 3 (59.4%) of “composite” individuals is higher than the same stage of “trader” individuals (54.5%).

Pearson's Chi-square test establishes a relationship between career path and stage of diagnosis. However, this relationship is weak to conclude to an interdependence.

Table 6: Educational typologies by stage

	Stage 1	Stage 2	Stage 3	Stage 4	<p><i>Khi-2 de Pearson:</i> X=8,2831, ddl=9, p-valeur=0,5059</p>
None	10%	5%	55%	30%	
Primary	0%	7,1%	64,3%	28,6%	
High School	4,8%	23,8%	61,9%	9,5%	
College	0%	0%	66,7%	33,3%	

Source : DAYORO Arnaud KOUASSI Tanoh ,AHUIE AssianAgnes Chantal, 2018

Table 6 shows that individuals with no level of study have the lowest rate of late diagnosis, as Stage 1 is 55% and Stage 2 is 30%, the cumulation is 80%. On the other hand, individuals with a higher level of education have no early diagnosis. In addition, they have the most advanced diagnosis rate, the highest with 33.3% of stage 4. In contrast, high school individuals have the lowest advanced diagnosis rate (stage 4: 9.5%) and a high early diagnosis rate. They have a cumulative rate of 28.6%, of which 4.8% is stage 1 and 23.8% is stage 2. Individuals at the primary level have an early diagnosis rate (cumulative stage 1 and 2: 7.1%) lower than the very advanced diagnosis rate (stage 4: 28.6%).

Pearson's chi-square test establishes a relationship between educational background and stage of diagnosis. However, this relationship is too weak to conclude that there is interdependence.

IV. DISCUSSION

The discussion is structured around two points, namely:

- Institutionalization of the delay in resorting to the Pediatric Oncology Unit
- Orientation of interventions for the reduction of the consequences of the delays of recourse

3-1 Institutionalization of the delay in resorting to the Pediatric Oncology Unit

This study shows that the diversity of life course trajectories presents regularities. Indeed, the analysis succeeded in categorizing the multiplicity of trajectories into reduced numbers according to the areas of life considered. This regularity reveals a standardization of the life course of the families of children with Burkitt's lymphoma (A. Gherghel and M.-C. Saint-Jacques, 2013) resulting from an institutionalization.

Under this aegis, the typology of family trajectories highlights a significant delay in recourse among individuals with a couple and de-cohabitation trajectory. Indeed, unlike individuals in families who benefit from a strong support network due to their proximity to the child's grandparents, the others are disadvantaged. Individuals close to family receive a material and symbolic contribution. However, the promotion of the new values of modernity creates social isolation, especially for individuals in cohabitation and de-cohabitation who seek autonomy and emancipation. The consequence is that in the event of illness specifically of a child, the parents of this child are left alone. In reality, this consequence is in line with the political choice made by Côte d'Ivoire in supporting children, which is that of parental responsibility (E. Maunaye, 2013). Thus, the promotion of the values of modernity and parental responsibility contribute to reducing the intensity of family solidarity, while the social security policy is discriminatory in Côte d'Ivoire. It only concerns individuals who have a job in the formal sector. In addition, the cost of private insurance automatically excludes parents from this study who have professional careers in the informal sector. According to the African Development Bank (AfDB, 2018), the average amount to be paid for a health insurance contract is between 13,000 FCFA and 18,000 FCFA per month, while incomes are precarious in the informal sector. This situation explains the delay in making significant use of the Unit for individuals who have a farmer and craftsman background who do not have a single case of early diagnosis.

In addition, individuals at secondary school level and higher have the highest rates of delays in using the Unit. This observation shows that the problem of the delay in recourse is not relative to the level of education, but to knowledge of Burkitt's lymphoma. It is relegated to the background behind adult cancers and pathologies in children such as HIV, malaria, diarrhea, malnutrition, etc. Lack of knowledge leads to the adoption of a standard

care course consisting of the use of traditional African medicine, self-medication, traditional Chinese medicine and the use of health care services. In this description, the transition to traditional African medicine is the most important. These are habits acquired during the socialization process (Y. E. P. Kouakou, 2015). Despite the socio-economic and structural transformations, African traditional medicine is revalued and its interest is constantly growing (S. Abayomi, 2010). On the other hand, B. M. Yoro (2012) places the importance of the transition to traditional African medicine in a perspective of social inequality. In reality, the precariousness of the national economy leads to a shortage of material and human resources, which is moreover unevenly distributed. This unequal distribution justifies that there are so many late recourses from individuals from outside the city of Abidjan. The unequal distribution indicates that there are health centers, however the duration of the transitions stipulates that the medical personnel ignore the symptoms of Burkitt's lymphoma to refer children suspected of this pathology to the Unit.

Ultimately, this article reports a standardization of life courses and an institutionalization of the delay in recourse. This delay in recourse constitutes a waiver of treatment. However, a destandardization of courses is at work. It is manifested by intra- and extra-group heterogeneity. This destandardization explains the inequalities in the diagnosis rates of Burkitt's lymphoma of children in Côte d'Ivoire.

However, the results should be interpreted with caution, since the choice of the number of classes reflects a desire to obtain relevant classes in order to facilitate the description. Also, this method did not allow to take into account simultaneous transitions, common types of processes when considering the period. Another aspect undoubtedly remains the selection of individuals and the statistical treatment with a probabilistic sample. Admittedly, the elements mentioned call for using these results sparingly, however, they do not invalidate the results.

3-2 Orientation of interventions for the reduction of the consequences of delays in recourse

The contribution of this article comes down to communication tracks that value intentionality in order to bring out a new behavior for change. About change, the new values do not necessarily imply the rejection of the old ones, but an integration of these, could preserve the fabric of intergenerational solidarity to break the cycle of social isolation of individuals in couples and those who have known several de-cohabitation transitions.

For families, a communication on Burkitt's lymphoma will allow them to know the pathology with a particular emphasis on individuals with a professional career of farmer and craftsman.

Similarly, at the level of traditional therapists, training sessions on the symptoms of Burkitt's lymphoma would help maintain their credibility and their role in the course of care. This role includes the responsibility of referring all suspicions of Burkitt's lymphoma to the pediatric oncology unit. Such training of traditional therapists combined with capacity building of care staff in the primary and secondary care delivery system will reduce the health risks associated with Burkitt's lymphoma for families.

At the level of the National Cancer Control Program (PNLCA), training will be democratized by carrying out online training or online courses. These training courses may be certifying and/or qualifying. They must be open to all and take into account individuals who have no educational level. The promotion and communication of the platform can make it a reference adapted to the realities of Côte d'Ivoire.

V. CONCLUSION

In recent years, childhood cancers have been on the rise. Burkitt's lymphoma is the dominant pathology. However, late diagnoses indicate a delay in accessing the reference center, and the health risks do not only weaken the security of the family, but also hinder the development of the entire community. Faced with this phenomenon, the study proposes to explain through the trajectories of the life course of families, the delay in recourse. Thus, a quantitative approach allowed the analysis of the life experiences of 58 individuals affiliated with the Pediatric Oncology Unit of the University Hospital of Treichville in Abidjan. Statistical operations with R's TRAMINER indicate that multiple pathways can be typified according to domains. Moreover, the distribution of these typologies shows a differential distribution when they are associated with the different stages of diagnosis of Burkitt's lymphoma in children.

Undoubtedly, all the typologies denote the late recourse to the Unit, nevertheless, individuals with a couple life and living apart experience record higher rates because they have fewer supports. In addition, the precariousness of income, especially for individuals who work as farmers and craftsmen, particularly outside Abidjan, induces a long transition to traditional African medicine during the course of care. At this stage, ignorance of Burkitt's lymphoma prolongs treatment attempts. Also, when the family arrives at the health department, the care staff does not immediately refer the child to the Oncology Unit because they do not immediately suspect cancer.

The analysis shows that several life course factors are involved in this phenomenon. Also, strategic intervention proposals have been formulated to contribute to a change in the management of Burkitt's lymphoma in Côte d'Ivoire.

Finally, the study reveals an institutionalization of the delay in recourse to the Unit and a standardization of the courses, obviously a destandardization is in progress because, the typologies are not homogeneous.

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Annexe1 : Grille du calendrier des parcours de vie

		<i>Heure de début :</i>	<i>Heure de fin :</i>			<i>Numéro de la fiche de collecte :</i>		
<i>Identifiant enquête :</i>						<i>Nom de l'enquêteur :</i>		
<i>Lien de parenté avec l'enfant :</i>			<i>Date de collecte :</i>		<i>Durée entretien :</i>			
<i>Année/ Age</i>	<i>Parcours familial</i>		<i>Parcours Education l- Profession nel</i>	<i>Parcours Résidentiel</i>	<i>Parcours de Soins</i>			<i>observ ations</i>
	<i>Evènemen t</i>	<i>Nomb re indivi du</i>	<i>Education / Etude Activité professionn elle</i>	<i>Lieu résidence</i>	<i>Maladie / Episode cancer</i>	<i>Typ e reco urs</i>	<i>Memb re initiat eur recour s</i>	

Sources : Grille de A. Gherghel et M.-C. Saint-Jacques (2013) adaptée par KOUASSI Tanoh 2018