

# Quality of Life as a Predictor of Childhood Cancer Treatment Abandonment

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## ABSTRACT

**Background:** Childhood cancer comes with a huge burden of medical and economic consequences on the child and family. The toxicities associated with treatment causes increased morbidity, and impact on their quality of life. This study set out to compare the quality of life of children adhering to cancer treatment versus children that abandon treatment using the Lansky play performance scale score indices. **Methodology:** The study was a prospective, hospital-based survey in two tertiary paediatric oncology centres in north-western Nigeria conducted between February–August 2022. Consecutive patients registered for cancer treatment were enrolled, and data depicting demography, pathologic diagnosis and treatment outcome was collated. Cases without a confirmed histologic/cytologic diagnosis of cancer were excluded. The Lansky play performance scale (LPPS) was used to assess the quality of life, and categorized as fully active, normal (score 100, Group I); mild restriction (score 70-90, Group II); moderate restriction (score 50-60, Group III); severe restriction (20-40, Group IV) and disabled (score 0-10, Group V). **Results:** There were 51 patients in the study, aged 1-16 years (mean 7.2+3.8), male : female ratio 1.4:1. There were 12(23.5%) leukaemia, 11(21.6%) retinoblastoma, 10(19.6%) lymphoma, 9(17.6%) rhabdomyosarcoma, 6(11.8%) neuroblastoma, 2(3.9%) neuroblastoma and 1(2.0%) carcinoma cases. Treatment related adverse events occurred in 20(39.2%) patients. The LPPS scores were: Group I - 15(29.4%), Group II - 18(35.3%), Group III - 4(7.8%), Group IV - 13(25.5%), Group V - 1(2.0%). There were 33(64.7%) patients on follow-up, 10(19.6%) mortalities and 8(15.7%) cases of abandonment. In the abandonment category, 4(50%) were LPPS Group I, 3(37.5%) Group II and 1(12.5%) Group III. In addition, 6(75%) had no change in LPPS, while 1(12.5%) each had a positive change and negative change respectively. The risk of abandonment was not statistically significant based on LPPS. **Conclusion:** The study found that treatment abandonment was commoner among patients with normal or mild impairment of play activity.

**Key-words:** Childhood Cancer, Quality of Life, Lansky Play Performance Scale, Treatment Abandonment, Mortality

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## INTRODUCTION:

A diagnosis of childhood cancer comes with a huge burden of medical, psychosocial, emotional and economic consequences on the child and the family.<sup>[1]</sup> In addition, the toxicities associated with the cancer treatment cause an increase in morbidity which further adds to the distress encountered by the patients and their families.<sup>[2]</sup> These undoubtedly impacts on the quality of life of the child with cancer.<sup>[3]</sup> In particular, a reduction in physical activity and autonomy has been documented in children undergoing cancer treatment.<sup>[1]</sup> The Lansky play performance scale is a tool that assesses the activity of daily living of a child with cancer, and has been validated to be a fair index of quality of life in children with cancer.<sup>[4]</sup> It is routinely used in cancer clinical trials to measure treatment related morbidity, tolerance and outcomes by the observation of the child's play activity. It is simple, convenient, reproducible, and provides a quantifiable measurement of the child's performance.<sup>[8]</sup>

In many low and middle income countries, treatment for childhood cancer is privately funded or out-of-pocket expenditure by the families. This is coupled with the indirect costs of lost wages or income for the parent while looking after the child. Cancer care has been estimated to consume more than 40 times an average family's monthly income.<sup>[9]</sup> Therefore, many patients end up abandoning treatment mostly due to financial exhaustion.<sup>[10]</sup>

There are many studies on the predictors and associations of childhood cancer treatment abandonment.<sup>[11-14]</sup> However, not much is known about the link between quality of life and cancer treatment abandonment in children. Therefore, this study set out to compare the quality of life of children adhering to cancer treatment versus children that abandon treatment using the Lansky play performance scale score indices.

## METHODOLOGY:

The study was a prospective, hospital-based survey

in two tertiary health facilities treating childhood cancers in north-western Nigeria; conducted between February–August 2022. Sample size was calculated using Krejcie and Morgan's table.<sup>[15]</sup> Consecutive patients registered for cancer treatment were enrolled, and data depicting demography, pathologic diagnosis, staging of disease, treatment received, and treatment outcome was collated. However, cases without a confirmed histologic/cytologic diagnosis of cancer were excluded from the analysis.

The Lansky performance scale was used to assess the child's status at enrolment and during each hospital visit for the duration of the study, with the last documented visit considered the exit from the study. The Lansky scale is a parent-rated assessment of the child's play activity as the index of performance.<sup>[6]</sup> Similar to the Karnofsky performance scale widely used in adult cancer, the Lansky scale is rated in deciles.<sup>[6]</sup> Level of activity is described in terms of active play and degree of physical limitation or independence. The scores range from fully active, normal (score 100; Group I), mild restriction (score 70-90; Group II), moderate restriction (score 50-60; Group III), severe restriction (20-40; Group IV) and disabled (score 0-10; Group V).

An interviewer-administered questionnaire was used during each hospital visit to ascertain the knowledge of childhood cancer from the parent and their perceptions about the child's well-being and the parents' employment or domestic demands and source of treatment financing. No follow-up interview was done to parents that abandoned treatment, as they were not available for the interview.

The study outcomes were mortality, abandonment or follow-up. Mortality was considered, as a death which occurred in hospital. Treatment abandonment was defined as failure to complete a curative therapy; or missing treatment for a consecutive period of four weeks or more; or refusal to initiate medically indicated treatment.<sup>[17]</sup> Follow-up was considered when a patient was still receiving a course of treatment in hospital or was

on home leave and expected back to hospital before the end of four weeks; or had completed a treatment regimen and was seen in clinic during the study period.

Ethical clearance was obtained from the Health Ethics and Research Committees of both institutions, and the patients were treated with confidentiality according to the Helsinki declaration. The data was analysed using SPSS v.16. Descriptive statistics were given as percentages or mean and standard deviations. Multi-variate analysis, odds ratio and risk ratio were used to show the relationships between predictors and outcome variables. The 95% confidence interval and p-value <0.05 were chosen as desired levels of significance.

## RESULTS:

There were 51 patients enrolled in the study, with an age range 1-16 years, (mean 7.2+3.8). The male to female ratio was 1.4:1. The age group distribution was 1-5yr 20(39.2%), 6-10yr 20(39.2%), 11-15yr 10(19.6%) and 16yr+ 1(2.0%). Patients had encountered symptoms of the illness for 1-36 weeks, (mean 4.5+6.6) prior to presentation, and 47(92.2%) had visited one or more health facilities before eventually being seen at the oncology unit. At least 37(72.5%) of the patients were residing in the state where the oncology unit was located, while 14(27.5%) were not residing within the state where the oncology unit was located. The number of days on admission were 1-95 days, (mean 18.3+19.2).

Diagnosis and treatments of the study patients

Table-1 below shows the distribution of diagnosis, tumour sites and staging for the study. The 10 lymphoma cases were made up of Burkitt's lymphoma 5(9.8%), non-Hodgkin's lymphoma 3(5.9%) and Hodgkin's lymphoma 2(3.9%).

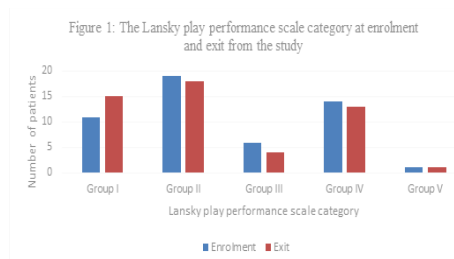
**Table-1: The distribution of diagnosis, tumour sites and staging for the study**

Diagnosis	n=51(100%)
Leukaemia	12(23.5%)
Retinoblastoma	11(21.6%)
Lymphoma	10(19.6%)
Rhabdomyosarcoma	9(17.6%)
Nephroblastoma	6(11.8%)
Neuroblastoma	2(3.9%)
Carcinoma	1(2.0%)
Site of tumour	
Head and Neck	15(29.5%)
Orbit	12(23.5%)
Blood	12(23.5%)
Abdomen	9(17.6%)
Perineum	3(5.9%)
Tumour stage	
II	9(17.6%)
III	16(31.4%)
IV	12(23.5%)
Not applicable	14(27.5%)

In terms of surgical procedures performed, 29(56.9%) had biopsies done from various tissue sites. There were 4(7.8%) nephrectomies and 1(2.0%) each of colostomy, debulking, enucleation and laparotomy. Chemotherapy was done in 48(94.1%) of the patients while none underwent radiotherapy.

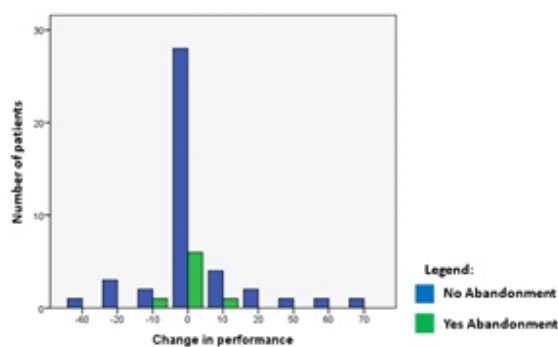
Treatment related adverse events were recorded in 20(39.2%) of the study. These comprised of pancytopenia 9(17.6%), sepsis 8(15.7%), bleeding 5(9.8%), neutropenia 3(6.0%), thrombocytopenia 3(6.0%), anaemia 2(4.0%), tumour lysis 1(2.0%) and vomiting 1(2.0%). Play performance scale scores

Figure-1 below depicts the Lansky play performance scale categorization of the patients at the time of enrolment and the exit from the study respectively.



It can be discerned from figure-1 that there was an increment of 36.3% in the number of patients with normal performance (Group I) at the end of the study, while there was a 5.3%, 33.3% and 7.1% reduction in number of patients within Groups II, III and IV performance respectively. There was no change in the number with Group V. Overall, there were 34(66.7%) of patients who had no change in their Lansky score at the end of the study, while 10(19.6%) had a positive change or gain in the score, and 7(13.7%) had a negative change or reduction in the score at the end of the study. Outcomes of the study and influence of quality of life on abandonment Among the 51 patients in the study, there were 8(15.7%) abandonment cases, 10(19.6%) mortalities, while 33(64.7%) were still receiving treatment at the end of the study period (follow-up). Comparing the LPPS in the treatment abandonment category, 4(50%) were in Group I, 3(37.5%) were in Group II and 1(12.5%) was in Group III. No patients abandoned treatment from Groups IV and V. In addition, 6(75%) of the abandonment group had no change in their Lansky score, while 1(12.5%) each was in the positive change and negative change groups respectively as shown in Figure-2.

Figure 2: Relationship between change in LPPS and abandonment.

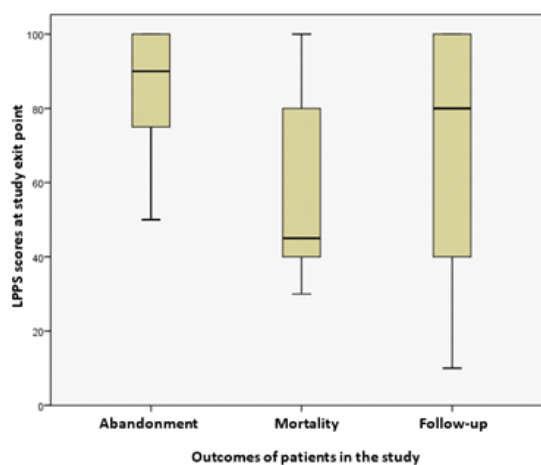


Further sub-group analysis showed that the risk of abandonment in the groups with normal activity or mild impairment, Groups I and II combined was more than three times likely; risk ratio 3.8 (0.51-28.6), p-value 0.1418. Likewise, the risk of abandonment in the no change group was 1.5 (0.34-

6.66), p-value 0.5860; positive change group 0.59 (0.08-4.23), p-value 0.5813; and the negative change group 0.90 (0.13-6.23), p-value 0.9126; when either of the groups is considered in isolation as a predictor of abandonment.

The relationship between the final performance score and the study outcomes is further depicted in Figure-3 below.

Figure 3: Relationship between LPPS score at exit point and study outcomes



Cost of treatment and source of financing

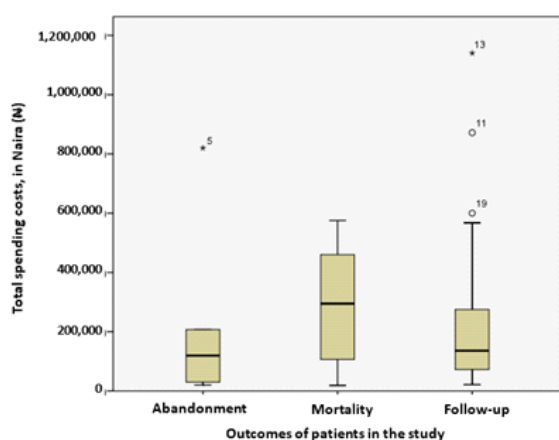
All but two of the patients used out of pocket expenditure to cover some or all of the cost of the treatment, 49(96.1%). Only 4(7.8%) had access to health insurance (through the national health insurance scheme - NHIS), two of whom said it was their sole source of funding at the time. There were 17(33.3%) who had received some financial donations from other sources, to supplement the out of pocket expenses. Table-2 below further gives a breakdown of the treatment costs.

Table-2: Costs incurred by the patients during treatment

	*Cost (Nigerian naira, ₦)	Mean	Std. Deviation
Total spending	18,400- 1,140,000	250,892.7	273,514.586
Medication costs	11,700- 642,000	164,817.37	146,869.523
Investigation costs	3,700- 230,000	66,684.21	65,819.604
Food/ Accommodation	3,000- 350,000	85,705.88	87,665.033
Other costs	1,000 300,000	43,935.29	81,698.814

\*Nigerian national minimum wage = N30,000/ US Dollar 67.67, as at Nov 2022. The effect of treatment costs and the patient outcomes are represented in figure-4 below, which shows a much lower spending in patients that abandoned treatment compared to other outcomes. Influence of caregiver decision making, perceptions, knowledge and challenges encountered on abandonment.

Figure 4: Total spending costs of the patients, in relation to study outcomes



In 26(51.0%) of the patients, fathers alone were said to have made the decision to bring the child to hospital, while 6(11.8%) mothers alone made the decision, and 12(23.5%) both parents jointly made the decision. However, in 7(13.8%) other relatives made the decisions. The caregivers of the patients were asked, if children could get cancer, and 37(72.5%) answered yes. There were 24(47.1%) caregivers who said they were missing work or income while staying in hospital, and 26(51.0%) said they had other activities that needed their attention elsewhere while being in hospital with their child. Only 19(37.3%) admitted to have received some form of support during the course of the hospital stay, and 26(51%) felt the hospital environment was conducive for their stay. However, 6(11.8%) of the caregivers said they suffered some physical ailments which was inconveniencing their stay in hospital. The relationship of these variables and treatment abandonment is given in Table-3 below.

**Table-3: Selected predictors of treatment abandonment in the study**

Variables	Risk ratio (CI)	P-value
Father made decision to come to hospital	0.96 (0.27-3.43)	0.9518
Caregiver missing work or income	1.13 (0.32-4.01)	0.8556
Caregiver has other activities at home	0.96(0.27 -3.43)	0.9518
Caregiver received support in hospital	1.68 (0.48-5.96)	0.4168
Caregiver has a physical ailment	2.5 (0.65-9.69)	0.2057
Caregiver said hospital environment was conducive	0.57 (0.15-2.16)	0.4062
Patient experienced an adverse event	0.93 (0.25-3.47)	0.9138

The decision to come to hospital made by mother, both parents and other relatives were also not statistically significant with regards to treatment abandonment.

## DISCUSSION

The study was conducted over a period of six months, and the number of patients enrolled was in keeping with the expected prevalence of childhood cancers in the two study sites based on previous published data.<sup>[1]</sup> There was a similar male to female ratio and spread of the patients among the different paediatric age groups. Thus it can be regarded as a fair representation of the study areas.

The mean duration of symptoms of four weeks before presentation to the oncology unit was long, and could be ascribed to the fact that all but four of the patients attended other healthcare facilities before eventually arriving at the oncology unit. Although the reasons for the lag time was not explored in the present study, other studies have shown that this type of pre-treatment centre delay can last up to 10 weeks due to failure to recognize the condition early or logistic and financial delays getting to the treatment centre.<sup>[20,21]</sup>

The pattern of cancer diagnoses is similar to what is available in the literature.<sup>[22-24]</sup> However, it is interesting to note that more than half of the tumours are related to the orbit, face, jaw or neck, as shown in Table-1. One would assume this should make the tumour visible at a much earlier stage compared to if the tumour was in the abdomen. Therefore, there is an opportunity to identify a lot of these patients at an early stage of the disease and refer for appropriate treatment, given that 92% had been seen at some health facility before presenting



to the oncology unit. This calls for a large scale health education and awareness of healthcare workers at all levels, to the signs and symptoms of childhood cancers and the appropriate referral pathways for treatment.

Also, it can be surmised from Table-1 that majority of patients had advanced stage disease at the time of enrolment. This could be linked to the earlier mentioned findings of long duration of symptoms before presentation at the oncology unit. The predominant treatment given was chemotherapy, which is in keeping with other studies. This can be explained in the present study by the advanced stage of disease in majority of patients and the significant portion of leukaemias and lymphomas among the diagnoses. In these situations, chemotherapy will be for cyto-reduction before surgery in the former, and for curative intent in the latter. Hence, the few number of surgical procedures to correspond with nephrectomies for nephroblastoma and debulking surgery for a rhabdomyosarcoma. However, the absence of radiotherapy in the study is due to lack of functioning facilities for external beam radiation in the north-west region at the time of this study.<sup>[25]</sup>

Haematological toxicities were the most frequent reported adverse events in this study. This highlights the need for supportive care services in order to improve the quality of care for these group of patients. Earlier studies have established the dearth of supportive care services in the region. Most of the patients in this study were managed with red cell transfusions, granulocyte colony stimulating factors and antimicrobials according to the local protocols.

According to the Lansky play performance scores, there were more patients with normal activity or mild impairment of activity (Groups I and II) compared to all the other groups combined as shown in Figure-1. This is surprising, given that more than half of the patients had advanced stages of disease at the time of presentation. The expectation would be that the advanced stages of disease will have more impairment of activity. Similarly, there were fewer patients who had a

reduction in their performance score compared to those who improved theirs or stayed the same. This is also surprising since more than a third of the patients had adverse events or toxicities reported, even though the toxicities were not graded. Perhaps, there were only mild adverse events, so the well-being of the patients may not have been significantly affected to reduce the performance scores.

The mortality and abandonment rates observed in this study appear to be lower than previously reported from the study sites.<sup>[1, 1]</sup> These can be explained by the shorter duration of observation in the present study. But in addition, there have been improvements in patients tracking and multi-disciplinary treatments across the centres.

Looking closely at Figure-2, it is evident that majority of patients who abandoned treatment did not experience a change in their performance scores. And combining this picture with the output of Figure-3, it is also evident that those who abandoned treatment were localized more in the region with high performance scores compared to the mortalities or those still on treatment that were spread across a wider region to involve lower performance scores. This suggests that patients that abandoned treatment were more playful and active than those that died or were still receiving treatment. Perhaps, a feeling that the child is not unwell enough to necessitate the treatment or even feeling that the child has recovered might influence the abandonment of the treatment. There is evidence to suggest that parents have abandoned cancer treatment for their children based on the perception that the child was not as unwell as the diagnosis suggested, and therefore the treatment was unwarranted.<sup>[26]</sup> However, neither the change in performance scores nor the final recorded performance status categories showed statistical significance as risk factors for treatment abandonment.

The source of funding for the patients was predominantly out-of-pocket as already established by earlier studies.<sup>[1, 1]</sup> However, the average spending on treatment recorded in this

study is very low compared to findings from a more affluent region of the country.<sup>[9]</sup> This low figures may be due to the reliance on memory recall in collecting the information on the spending and the patronage of vendors within and outside the hospital environment for some of the services. That notwithstanding, the obtained figures in this study are in multiples of the Nigerian national minimum wage. Therefore, this is supportive evidence that the treatment of childhood cancers in Nigeria is beyond the family income, and there is a need for the establishment of a payment scheme for childhood cancer services akin to what has been instituted for some adult cancers. Incidentally, the patients who abandoned treatment had the least spending for their treatment compared to the other outcomes as depicted in Figure-4. Perhaps, the abandonment was due to inadequate finances as supported by earlier studies.<sup>[26]</sup> The absence of a contact tracing system for patients that abandon treatment makes it difficult to directly ascertain from the parents other possible reasons that might have influenced their abandonment of the treatments.

More than half of parents or caregivers in the study had some challenges that appeared to affect their stay in the hospital ranging from missing income to having physical ailments. Among these factors only having a physical ailment in the caregiver was found to have a two-fold risk of abandonment. But this was not statistically significant. However, some of these factors have been shown to influence abandonment previously.

## CONCLUSION

This study found that patients who abandoned treatment were predominantly of normal activity or mild impairment of play activity, but also had less total amount of financial spending for their treatments. This suggests that a caregiver perception of the child not being very ill and possibly not having enough money may have influenced the outcome of abandoning the treatment. There is need for larger studies in order to explore these assertions, but nonetheless this

calls for more attention to the issue of treatment abandonment and affordable treatment in order to improve childhood cancer survival indices in the region.

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