

ORIGINAL RESEARCH

# Caregivers satisfaction with care received by paediatric oncology patients admitted at the University Teaching Hospital-Lusaka Zambia

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## ABSTRACT

**Background:** Diagnosis of cancer is a traumatic event that does not only affect the diagnosed patients but also their caregivers. Supportive interventions are therefore essential for the caregivers to go through the cancer pathway and attain a sense of satisfaction for both medical and none medical services. Therefore evaluating the extent to which patients and their caregivers are satisfied with health services is clinically relevant as satisfied patients are more likely to comply with treatment, take an active role in their own care, continue using medical care services and stay under the care of a health provider.

**Methods:** This was a descriptive cross-sectional study that investigated caregiver satisfaction with care received by paediatric oncology patients at the Paediatrics University Teaching Hospital, Lusaka-Zambia. Purposive sampling was used to select study participants and all caregivers who were available in the paediatric oncology ward at the time of data acquisition were selected resulting into a sample size of 50 caregivers. Data was collected using a structured interview schedule.

**Results:** More than half 26 (52%) of the respondents were knowledgeable about cancer disease, 13 (26%) were partially knowledgeable with only 11 (22%) were not knowledgeable. Despite high knowledge levels, 19 (38%) did not know the cancer stage of their child. The majority 30 (60%) of patients had partial access to cancer treatment with only 3 (6%) who reported having full access to treatment. Concerning professional support, majority 47 (94%) received good or very good support from the staff while only 3 (6%) received poor support. When all the factors assumed to influence satisfaction were considered, 18 (36%) of the respondents were very satisfied, 19 (38%) were partially satisfied with only 13 (26%) who were not satisfied with care received. Of the five factors which were hypothesized to influence caregiver satisfaction, only professional support had a significant association with caregiver satisfaction with a *p* value of .004.

**Conclusions:** Only professional support had a significant association with caregiver satisfaction against all other factors hypothesized to influence satisfaction, implying that if appropriate profession support is given, caregivers are more likely to get satisfied with care and consequently comply with treatment.

**Key Words:** Caregivers, Satisfaction, Care, Paediatric oncology patient

## 1. BACKGROUND

Globally, about 43 children are diagnosed with cancer every day, 40,000 undergo treatment and 12% do not survive every

year.<sup>[1]</sup> In Great Britain, researchers predicted that 1 in 500 children will develop some form of cancer by 14 years of age with Leukaemia being the most commonly diagnosed cancer

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in children.<sup>[2]</sup> In sub Saharan Africa, It is difficult to measure the incidence of childhood cancer accurately. Cases are often unreported with greater frequency of death from infectious diseases and malnutrition.<sup>[3]</sup> According to Chintu,<sup>[4]</sup> Zambia has recorded an increase in the occurrence of total childhood cancers with lymphoma being the commonest reported childhood malignancy followed by retinoblastoma and Kaposi's sarcoma.

With regard to survival, Smith, 2010 asserts that childhood cancer survival rates are high in high income countries (HICs) and have continued to improved dramatically over the past half century. Global studies have revealed that advances in treatment have increased the overall 5 year survival rate while in the 1960s it was 30% and is now nearly 80%.<sup>[5]</sup> Contrary to the situation in high income settings, childhood cancer survival rate in many countries of Sub Saharan Africa remains low due to late diagnosis and poor access to treatment.<sup>[6]</sup> Zambia for example, has recorded poor treatment completion rates which are due in part to the logistical challenges faced by families, low educational status, and significant distance from the hospital.<sup>[7]</sup>

Diagnosis of cancer is a traumatic event.<sup>[8]</sup> It does not only affect the patient but also their caregivers. Therefore, evaluating the extent to which patients and their caregivers are satisfied with health services is clinically relevant as satisfied patients are more likely to comply with treatment, take an active role in their own care, continue using medical care services and stay within a health provider. According to Bowman,<sup>[8]</sup> supportive interventions are essential for the caregivers to go through the cancer pathway since diagnosis does not only affect the patient but also devastates and traumatizes their caregivers as both patients and caregivers face substantial needs. Davies et al.<sup>[9]</sup> define a family caregiver as an unpaid family member, friend, or neighbour who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care.

Considering that caregivers play an important role in providing social and emotional support for the cancer patients and influence how well patients manage their health, supportive interventions are essential for these caregivers.<sup>[10]</sup> Studies have reported that knowledge and psychosocial support are the common caregiver needs. Peterson and colleagues,<sup>[11]</sup> states that low social support as well as care giving burden induced stress and anxiety are common among cancer caregivers. Further literature attests that caregivers experience physical problems such as fatigue, pain, sleep problems and psychological distress. As for the Paediatric Oncology

patients, the top five identified needs for both patients and caregivers are social work services, play activities during treatment and insurance to cover medical care. Others are educational activities, and cancer-related medical services.<sup>[11]</sup>

Davies and colleagues,<sup>[9]</sup> further reported a reduction in burden and distress for caregivers who receive friendly, socially supportive phone calls that provided some respite from care giving, even without in-home caregiver skills training. Furthermore, home visits and enhanced social support also can help reduce caregiver depression. Studies found that family caregivers of patients with advanced cancer reported psychological support and a range of information needs of a practical nature including pain control, weakness and fatigue, home care services, management of depression, management of weight loss and appetite loss.<sup>[12]</sup>

Due to the physical stress, psychological distress at times depression and disruption to identity and family structure that caregivers experience<sup>[11,13]</sup> it is important to measure their level of satisfaction with care they receive. According to Hannon,<sup>[14]</sup> satisfaction with care is important for quality assurance in oncology. Satisfaction is defined as the extent of an individual's experience compared with his or her expectations.<sup>[15]</sup> Evaluating the extent to which patients are satisfied with health services is clinically relevant as satisfied patients are more likely to comply with treatment, take an active role in their own care, continue using medical care services and stay within a health provider.<sup>[16]</sup>

Caregivers seem to desire greater involvement in treatment decisions.<sup>[14]</sup> Therefore, every clinical system needs to recognize the caregiver's role in patient care and partner with the caregiver as well as the patient to deliver patient and family centred care. Consequently, designing a system that not only supports but fosters caregiver engagement can increase caregiver satisfaction and need fulfilment.<sup>[17]</sup> Many factors are involved in determining caregivers' satisfaction such as need for attention, support, continuity and communication. According to Sajjadi,<sup>[18]</sup> caregivers expect good service delivery and more appropriate services in order to promote satisfaction and to improve quality of life. The objective of this study therefore was to investigate factors influencing caregiver satisfaction with care received by paediatric oncology patients at the Paediatrics University Teaching Hospital, Lusaka-Zambia. It was hypothesized that there was no association between the caregivers' satisfaction with care received by paediatric oncology patients and the following factors; knowledge of condition and treatment outcomes, cancer staging of the child, physical dependence of the child, access to oncology treatment modalities and professional support.

## 2. MATERIALS AND METHODS

This study utilized a descriptive cross-sectional design. Purposive sampling was used to select study units. All caregivers who were available in the paediatric oncology ward at the time of data acquisition were selected. The sample size was therefore 50 caregivers because the ward has an average of 50 patients per month.

In this study, data was collected using a structured interview schedule. It consisted of questions that obtained information on demographic characteristics, knowledge of condition and treatment outcomes, cancer staging of the child, physical dependence of the child, access to treatment modalities and professional support. An informed consent was obtained from caregivers who agreed to participate in the study, prior to the administration of the interview schedule.

Data were analyzed using SPSS version 20 software computer package. Chi square test was used to test the association between dependent and independent variables. The cut off point for statistical significance was set at 5%. Therefore only  $p$  value of less than or equal to .05 was considered to be statistically significant.

## 3. RESULTS

Out of the 50 caregivers interviewed, majority 19 (38%) were above 42 years of age. There were more females 37 (74.0%) than males 13 (26%) caregivers with 34 (68%) who were married against 16 (32%) who were not married. Almost all 49 (98%) were Christians with only 1 (2%) was Buddhist. Majority of the respondents 34 (68%) came from outside Lusaka the capital city of Zambia while 16 (32%) were from within Lusaka. Almost two thirds of the respondents 32 (64%) were taking care of their biological child while 18 (36%) were taking care of a relative. With regard to education and employment status, Majority of the respondents 23 (46%) reached secondary school level while very few respondents 5 (10%) acquired tertiary education. Almost half of the respondents 24 (48%) were self employed while 10 (20%) were formally employed and 16 (32%) were unemployed.

Table 1 shows that 19 (38%) respondents did not know the cancer stage of the patient, however almost two thirds 32 (64%) indicated that their patients were able to carry out all activities of daily living, 15(30) were able to carry out some activities while 3 (6%) were unable to carry out any. With regard to knowledge of the condition, more than half 26 (52%) were knowledgeable about cancer disease, 11 (22%) were not knowledgeable, while 13 (26%) were partially knowledgeable. Findings further revealed that majority of the respondents 30 (60%) could only partially access cancer treatment

with only 3 (6%) who report having full access to treatment. Concerning the support that the caregivers received, majority 47 (94%) indicated that they either received good or very good support from the staff while only 3 (6%) received poor support. When all the factors assumed to influence satisfaction were considered, 18 (36%) of the respondents very satisfied, 19 (38%) were partially satisfied with only 13 (26%) who were not satisfied with care received.

Of the five factors which were hypothesized to influence caregiver satisfaction; level of education, cancer stage of the patient, ability of patient to perform activities of living, access to cancer treatment and professional support, only professional support had a significant association with caregiver satisfaction as shown in table two.

## 4. DISCUSSION

Satisfaction is the fulfilment of one's wishes, expectations, needs or the pleasure derived from this. This study revealed that 19 (38%) of the respondents were partially satisfied with the care received, 18 (36%) were satisfied with care received while 13 (26%) indicated that they were not at all satisfied with care received. This shows that most of the respondents were at least satisfied with care and this could be attributed to the good professional support received and adequate information acquired about cancer condition.<sup>[12]</sup>

In this study, Professional support was the only variable that showed a significant association with Satisfaction with care in a chi-square test performed ( $\chi^2 = .004$ ). We therefore, rejected the null hypothesis which stated that there is no association between the caregiver's satisfaction with care received by Paediatric oncology Patients and Professional support.

Our findings are supporting findings of a study conducted by Nigel and colleagues,<sup>[19]</sup> in Canada in 2002 on parental satisfaction regarding the consultation of Paediatric patients with cancer as part of the evaluation of a change of the cancer treatment as previously done. The authors concluded that all parents appeared satisfied with the care received.

In another study by Mack and colleagues,<sup>[20]</sup> to evaluate the quality of care of Paediatric patients with malignant conditions conducted in America. It was established that out of the 144 parents interviewed, 70% of parents rated the quality of care by their medical oncologists as excellent, 12% as very good, 10% as good, 2% as acceptable, and 5% as poor quality of care. A greater number of those sampled were satisfied with care received. It could be assumed that in United States of America the standard of care is good and hence the satisfaction with medical services. Similarly, Ringdal,<sup>[21]</sup> in Norway conducted a study with the aim to assess family

Satisfaction with End-of-Life Care for Cancer Patients in a Cluster. The results revealed that caregivers were satisfied with care they had received.

**Table 1.** Factors hypothesized to influencing caregiver satisfaction with care and level of satisfaction

	Frequency	Percent (%)
<b>Cancer Stage</b>		
Stage 1	7	14.0
Stage 2	7	14.0
Stage 3	10	20.0
Stage 4	7	14.0
Doesn't know	19	38.0
Total	50	100.0
<b>Child's ability to carry out Activities of daily Living</b>		
All Activities	32	64.0
Some activities	15	30.0
None	3	6.0
Total	50	100.0
<b>Level of knowledge</b>		
Knowledgeable	26	52.0
Partially knowledgeable	13	26.0
Not knowledgeable	11	22.0
Total	50	100.0
<b>Access to cancer treatment</b>		
Easily Accessible	3	6
Partially Accessible	30	60
Not accessible	17	34
Total	50	100
<b>Professional Support</b>		
Very good support	10	20.0
Good support	37	74.0
Poor support	3	6.0
Total	50	100.0
<b>Level of Satisfaction with care</b>		
Very Satisfied	18	36.0
Partially satisfied	19	38.0
Not satisfied	13	26.0
Total	50	100.0

On the other hand, Sajjadi and colleagues,<sup>[18]</sup> in Iran assessed quality of life in caregivers of children with cancer and investigated the relationship between the caregivers' quality of services and satisfaction with care in the social work section. Results were that caregivers of children with cancer reported that they go through the cancer pathway and attain a sense of satisfaction for both medical and none medical services.

Other findings are further in line with a study conducted in India,<sup>[22]</sup> entitled needs of informal Caregiver of Terminally

Ill Cancer patients'. The study reported that most of the caregivers who were in middle age had no prior experience of care giving. The caregivers were however satisfied by the information and medical support provided to them by their treatment team. The unmet needs of the caregivers were homecare, psychological support, and financial help.

Another factor which was thought to influence satisfaction was the cancer stage of the patient. However for this study, a chi-square test showed no significant relationship between

level of satisfaction with care and cancer staging of the child ( $\chi^2 = 0.769$ ). Weller<sup>[23]</sup> describes cancer staging as the severity of an individual’s cancer based on the magnitude of the original primary tumour as well as on the extent cancer has spread in the body. From a sample of 50 respondents 19 (38%) did not know the cancer staging of their patient, while

the rest of the caregivers were able to indicate cancer stage of their patients. Regardless of most caregivers being knowledgeable on their patients’ condition, the majority did not know the cancer stage of their children. This could be due to delayed investigations to confirm diagnosis.

**Table 2.** Caregiver Satisfaction versus, level of education, cancers stage of the patient, performance of activities of living, access to cancer treatment and professional support

		Highest Level of Education of the Caregiver					Total	p-value
		Primary	Secondary	Tertiary	Not schooling			
Level of Satisfaction with care	Satisfied	6 (12%)	7 (14%)	3 (6%)	2 (4%)	18 (36%)	<b>.720</b>	
	Partially Satisfied	6 (12%)	8 (16%)	1 (2%)	4 (8%)	19 (38%)		
	Not Satisfied	3 (6%)	8 (16%)	1 (2%)	1 (2%)	13 (26%)		
	Total	15 (30%)	23 (46%)	5 (10%)	7 (14%)	50 (100%)		
		Cancer stage of the patient					Total	p-value
		Stage 1	Stage 2	Stage 3	Stage 4	Doesn't know		
Level of Satisfaction with care	Satisfied	4 (8%)	3 (6%)	2 (4%)	3 (6%)	6 (12%)	18 (36%)	<b>.769</b>
	Partially Satisfied	1 (2%)	2 (4%)	4 (8%)	3 (6%)	9 (18%)	19 (38%)	
	Not Satisfied	2 (4%)	2 (4%)	4 (8%)	1 (2%)	4 (8%)	13 (26%)	
	Total	7 (14%)	7 (14%)	10 (20%)	7 (14%)	19 (38%)	50 (100%)	
		Child’s Performance of Activities of Daily Living			Total	p-value		
		All of them	Some of them	None				
Level of Satisfaction with care	Satisfied	9 (18%)	7 (14%)	2 (4%)	18 (36%)	<b>.486</b>		
	Partially Satisfied	14 (28%)	4 (8%)	1 (2%)	19 (38%)			
	Not Satisfied	9 (18%)	4 (8%)	0 (0%)	13 (26%)			
	Total	32 (64%)	15 (30%)	3 (6%)	50 (100%)			
		Access to cancer treatment			Total	p-value		
		Easily Accessible	Partially Accessible	Not Accessible				
Level of Satisfaction with care	Satisfied	2 (4%)	12 (24%)	4 (8%)	18 (36%)	<b>.418</b>		
	Partially Satisfied	0 (0%)	12 (24%)	7 (14%)	19 (38%)			
	Not Satisfied	1 (2%)	6 (12%)	6 (12%)	13 (26%)			
	Total	3 (6%)	30 (60%)	17 (34%)	50 (100%)			
		Caregiver’s Level of Knowledge about the diseases			Total	p-value		
		Knowledgeable	Partially Knowledgeable	Not Knowledgeable				
Level of Satisfaction with care	Satisfied	9 (18%)	7 (14%)	2 (4%)	18 (36%)	<b>.316</b>		
	Partially Satisfied	9 (18%)	5 (10%)	5 (10%)	19 (38%)			
	Not Satisfied	8 (16%)	1 (2%)	4 (8%)	13 (26%)			
	Total	26 (52%)	13 (26%)	11 (22%)	50 (100%)			
		Professional Support			Total	p-value		
		Very good support	Good support	Poor Support				
Level of Satisfaction with care	Satisfied	7 (14%)	11 (22%)	0 (0%)	18 (36%)	<b>.004</b>		
	Partially Satisfied	3 (6%)	16 (32%)	0 (0%)	19 (38%)			
	Not Satisfied	0 (0%)	10 (20%)	3 (6%)	13 (26%)			
	Total	10 (20%)	37 (74%)	3 (6%)	50 (100%)			

With regard to knowledge of the condition as one of the factors that could influence satisfaction, this study revealed that the majority 26 (52%) of the respondents were knowledgeable about cancer disease, 13 (26%) were partially knowledgeable while 11 (22%) were not knowledgeable. For our study, knowledge was measured using knowledge test component of the interview schedule. The knowledge levels were therefore determined using the ability to define cancer, state the signs and symptoms and indicate treatment and common side effects. Therefore those who scored between 7-10 on the knowledge questions were regarded as knowledgeable; those who scored between 4-7 were regarded as partially knowledgeable while those who scored below 4 were regarded as not knowledgeable. The finding that majority of the respondents were knowledgeable, could be attributed to good professional support and long hospital stays which made caregivers understand their children's conditions better and became more knowledgeable about the condition. However, there was no significant statistical relationship between level of satisfaction with care and level of knowledge ( $\chi^2 = 0.316$ ).

Our study findings on knowledge are in agreement with those of a study conducted by Iconomou<sup>[24]</sup> in Greece. The objective was to identify the specific informational needs of primary caregivers of cancer patients receiving chemotherapy in a Greek outpatient setting and to assess their preference for cancer-specific booklets, their levels of satisfaction with communication and their psychological status. The main findings were that a significant proportion of the caregivers had elevated needs for information, which were positively associated with a preference for cancer-specific printed material but negatively associated with satisfaction with the doctor's communication of information and affective behaviour. Participants expressed preference for printed material and were satisfied with communication. The results suggest that the Greek cancer caregiver needed more factual information relevant to the patient's condition and that communication of information is critical if caregivers are to be satisfied.

This is also supported by a study conducted by McKenna et al.<sup>[25]</sup> in UK with the aim to evaluate Parental involvement in paediatric cancer treatment decision. The study investigated parents' information needs and involvement in decision-making processes affecting the care of children diagnosed with cancer. Parents reported that doctors contributed almost twice as much to the decision-making process as they did, but parental satisfaction positively correlated with the amount of information provided when giving informed consent. Information and support tailored to parents' specific needs may therefore enhance satisfaction with clinical decision making and reassure parents about decisions made in

the long-term interest of their child's health.

Another factor that was assumed to influence satisfaction was accessibility to cancer treatment modalities. The findings of our study revealed that out of a sample of 50 respondents the majority 30 (60%) could partially access treatment as these stayed outside Lusaka where the only cancer diseased hospital in the country was located. A small number 3 (6%) easily accessed treatment. These were coming from within Lusaka, few minutes away from cancer treatment facility while 17 (34%) responded that cancer treatment was not accessible. This indicated that distance from the hospital had an influence on accessibility to treatment and was likely to affect satisfaction with care. However, a Chi Square test performed to assess the association between access to treatment and caregiver satisfaction revealed that there was no association between level of satisfaction and access to cancer treatment ( $\chi^2 = .418$ ,  $df = 4$ ,  $p > .05$ ).

Findings of our study supports are in agreement with those of a study conducted in California by Lavergne and colleagues,<sup>[26]</sup> highlighted socio-demographic variables such as patients' income as factors which limit access to treatment modalities. Lavergne et al.<sup>[26]</sup> argued that those families from low income groups had lower rates of consultations and utilization of various treatment modalities in California. Other patient dependent barriers to access included lower education level and lack of support. In addition easy accessibility to the hospital which offers cancer treatment were suggested to motivate caregivers to take their patients for treatment promptly and as scheduled. Similarly, Walker<sup>[27]</sup> conducted a study in Tanzania about perception of family cancer care givers. Results from the study suggested that caregivers in Tanzania experience challenges in meeting their needs during the care situation. Limited resources made it difficult to afford transportation to and from health centres and to provide food for the family and the patient. Findings of such studies suggest the importance of access to cancer treatment facilities in the promotion of patient and caregiver satisfaction.

Caregiver burden has been reported to affect satisfaction with care.<sup>[28]</sup> As a means for determining caregivers burden for our study participants, the caregivers were asked on the ability of their patients in carrying out activities of daily living. The findings were that, majority 32 (64%) indicated that their patients were able to carry out all the activities of daily living. The other 15 (30%) were able to carry some activities of daily living while 3 (6%) were not able to carry out any activities of daily living. Contrary to our assumption, that physical dependability is associated satisfaction with care, our study findings revealed that there was no association

between Physical dependence of a child (ability to carry out activities of daily living) and satisfaction ( $\chi^2 = 0.486$ ).

Our findings are contrary to those a study conducted in Korea<sup>[28]</sup> entitled burdens, needs and satisfaction of terminal cancer patients and their caregivers. Terminally ill cancer patients and caregivers were interviewed to determine how much burden they experienced and to establish what factors are most important for satisfaction in advanced cancer stage. The study revealed that the burden was great in both terminal cancer patients and their caregivers and was perceived to be more severe by caregivers. The study further indicated that burden was the factor for satisfaction with care in both groups. The caregivers felt more burdened and placed greatest emphasis on discussion about further treatment plans as this influenced satisfaction with care.

### Study limitation

The sample comprised of only 50 purposefully selected respondents from University Teaching Hospital as such the findings cannot be generalized to other settings.

## 5. CONCLUSION

Out of the five factors which were hypothesized to influence caregiver satisfaction; level of education, cancers stage

of the patient, ability of patient to perform activities of living, access to cancer treatment and professional support, our study revealed that only professional support had a significant association with caregiver satisfaction. In literature, there have been varied findings regarding factors that influence caregiver satisfaction with care. Most scholar have agreed that appropriate environmental conditions, emotional support, professional support, factual information related to the patient's condition and need, homecare, and financial help are the major factors that influence satisfaction with care received by paediatric oncology patients while others have found no association between satisfaction and the stated factors. Our study has therefore added on to the discourse while pointing at professional support as having significant influence on caregiver satisfaction. To this effect, we recommend appropriate profession support including provision of information about the condition and treatment modalities, referral to sources of social and financial support, and advocacy to easy access to care. Such support can enable caregivers to realistically go through the cancer pathway and attain a sense of satisfaction for both medical and none medical services.

## CONFLICTS OF INTEREST DISCLOSURE

The authors declare no conflict of interest.

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