

# Assessment of Parents' Perception of Quality of Pediatric Oncology Inpatient Care at Kenyatta National Hospital

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## ABSTRACT

**Objective:** Adequate knowledge of parents' perception of quality of pediatric cancer care helps to identify the areas of care improvement which would contribute to disease outcome in regard to the quality of life and satisfaction with the care provided. The aim of the study was to assess the parents' perception of the quality of Pediatric Oncology Inpatient Care at Kenyatta National Hospital. **Methods:** A cross-sectional descriptive quantitative and qualitative study was undertaken using a pretested semi-structured questionnaire and a focused group discussion guide. Assessment of parents' perception of quality of care was done in relation to the institution's structures and care delivery processes. These included the ward environment, resources for cancer treatment, care processes, service providers, and parents' knowledge empowerment. Participants were systematically selected. Parents' perception was defined as satisfaction or dissatisfaction with the care provided. Data were analyzed using SPSS version 20.0 (Armonk, NY: IBM Corp.) and presented as frequencies and percentages. Chi-square was used to test the

significant association between variables. Level of significance was set at a  $P \leq 0.05$ . **Results:** A total of 107 respondents were interviewed and 57.9% were satisfied with the overall quality of care they received. The determinants of overall satisfaction in this study were found to be related to resources for cancer treatment (odds ratio [OR] = 3.10; 95% confidence interval [CI] = 1.39–6.90;  $P = 0.005$ ), care delivery processes (OR = 2.87; 95% CI = 1.28–6.43;  $P = 0.009$ ), and the ward environment (OR = 2.59; 95% CI = 1.17–5.74;  $P = 0.018$ ). **Conclusions:** The parents were moderately satisfied with the oncology care services their children received. The gaps identified in service delivery included those related to the availability of the required resources for efficient care delivery and also educational as well as psychosocial needs of the parents.

**Key words:** Parents, pediatric oncology, perception, quality of care

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## Introduction

Global childhood cancer morbidity and mortality is on the rise with about 200,000 children being diagnosed annually.<sup>[1]</sup> Low income countries account for 80% of childhood cancers and 90% deaths.<sup>[2]</sup> Kenya's annual childhood cancer incidence is 3000.<sup>[3]</sup> Provision of quality care can reduce childhood cancer deaths in low income countries where mortality is high.<sup>[4]</sup>

The demand for quality cancer care is on the increase. However, knowledge regarding the perceptions of what quality cancer care constitutes is inadequate.<sup>[5]</sup> Without assessing the parents' perception of what constitutes the quality care for childhood cancer patients, standards of care that meet parents' and pediatric cancer patients' needs and expectations may not be achieved. Evaluating patients' experiences provides vital information on their perception of the quality of care and treatment provided by the health care providers and the hospital as a whole. Factors affecting the provision of quality pediatric oncology care cannot be adequately addressed without establishing the parents' perspectives on the quality of care that their children receive. Since the outcome of childhood cancer patients greatly depends on the quality of care they receive, there is a need to evaluate the care provided to this group of patients and their parents by establishing their perception regarding the quality of care provided.

Patients' health care outcomes are determined by the structural attributes of the settings in which care occurs and the processes of care.<sup>[6]</sup> According to the model by Avedis Donabedian, measurement of health care quality is based on the structures, processes of care, and outcome.<sup>[7]</sup> By interviewing the patients, information about the structures and processes and their influence on care outcome can be obtained.<sup>[6]</sup> This framework model was used for assessing the structures and care processes within the hospital and their combined influence on determining parents' perception of the quality of care of childhood cancer patients admitted at the health care facility.

According to this model, the structures of health care include the physical and organizational aspects of care settings such as facilities, equipment, personnel as well as operational and financial processes supporting provision of care.<sup>[8]</sup> In this study, the structures include the physical ward environment and the resources required for pediatric cancer treatment. Patient care processes include interactions between care givers and patients. These rely on the structures to provide resources and mechanism for those involved to be able to carry out patient care activities that aim at outcomes such as promotion of recovery, functional restoration, survival, and patient satisfaction.<sup>[8]</sup> Care processes involving

the way care is delivered include the technical and interpersonal aspects.<sup>[8]</sup>

Technical aspects involve timeliness and accuracy of diagnosis, coordination of care as well as appropriateness of therapy, whereas interpersonal aspects involve clinician - patient relationship, information, and involvement in decision-making.<sup>[7]</sup> In this study, care processes include patient - nurse/physician relationship and communication as well as health service provider factors such as a caring attitude, friendliness, politeness, and honesty. One of the outcomes of the care according to Donabedian includes client satisfaction. This is of great importance when measuring the quality of care. It provides information about the success of the health care provided in regard to meeting the client's needs and expectations. If patients are not satisfied, then health care is regarded to have not achieved its goal.<sup>[9]</sup> In this study, patient outcomes include parents' satisfaction with the care provided to children with cancer. Based on this theory, the study examined factors which determined the parents' perception of quality of pediatric oncology inpatient care in regard to their satisfaction with the care provided. These factors include the ward environment, resources for pediatric cancer treatment, care delivery processes, and service provider factors such as attitude and caring behaviors. Parents' knowledge empowerment factors such as information, involvement in care, and decision making as well as support were also assessed.

The objective of the study was to assess the parents' perception of quality of pediatric oncology inpatient care and establish their level of satisfaction with the care provided. This would help in achieving standards of care that meet parents' and childhood cancer patients' needs and expectations in accordance to the requirements of the World Health Organization (WHO) as pertains to quality care.<sup>[10]</sup>

The study intended to establish the viewpoints of parents of pediatric oncology inpatients in regard to the hospital's structures and processes involved in the delivery of health care. This was in order to establish how they affected the care received by these patients, while in hospital which eventually contributed to their disease outcome in regard to the quality of life and satisfaction with the care provided. Previous studies have shown that it is important to determine the parents' requirements in terms of information and emotional support in order to improve the services provided to the families. Physical, psychological, and educational needs of the parents of children with cancer require to be addressed by health care providers, and these can be established from their perspectives of the care provided.<sup>[11]</sup>

Without assessing the parents' perception of what constitutes quality care in childhood cancer patients, standards of care that meet parents and pediatric cancer

patients' needs and expectations may not be achieved. The study will help to inform policies and guidelines on pediatric oncology care that will be geared toward high-quality care provision and hence improve survival and quality of life of pediatric oncology patients and their parents. This information can be used by the hospital management in decision making in regard to setting of standards for pediatric oncology care as well as making policies that are aimed at improving the care of childhood cancer patients. This will enhance the satisfaction and quality of life of childhood cancer patients and their parents and also help in contributing towards achieving the fourth millennium development goal, which is aimed at reduction of child mortality.

## Methods

The study was carried out at Kenyatta National Hospital's pediatric oncology wards between May and July 2015. Kenyatta National Hospital is a 1800 bed capacity Tertiary Referral Hospital in Kenya. It is the largest in Eastern and Southern Sahara. The hospital's mandate is to provide specialized quality health care, facilitate medical training and research, and participate in National Health Policy. It is the Primary Teaching Hospital of the University of Nairobi and Kenya Medical Training College - Nairobi. It receives patients from various parts of the country as well as from East and Central Africa.

This was a descriptive cross-sectional study where both quantitative and qualitative data was collected to assess the parents' perception of the quality of pediatric oncology inpatient care at Kenyatta National Hospital's pediatric oncology wards.

The pediatric oncology wards where the study was carried out admits patients aged 0–12 years. Hence, that was the reason for including children up to the age of 12 years. Written informed consent to participate in the study was obtained from all the participants. Purposive selection of pediatric oncology wards was done, and systematic sampling was used to select study participants. Proportionate allocation of study participants based on the number of patients in each ward, and calculation of the sampling interval was done. Every second parent according to the patients' (children's) list in each ward was systematically sampled until the required number of participants in each ward was reached. The parents who were not subjected to a semi-structured questionnaire interview participated in the focused group discussion (FGD), and these were drawn from all the pediatric oncology wards. Pretesting of the study instrument was done to verify the data collection tool for reliability (Cronbach's alpha = 0.79) and face validity before data was collected. The pretest results were used

to improve the study tool for validity and reliability. The questionnaire used was a modification of Picker Institute Pediatric Inpatient Survey tool applied in the assessment of quality of care. Picker survey instruments are a reliable and valid measure for use in inpatient processes that affect the quality of care in inpatient settings. Its development and validation was based on data from inpatient survey in five countries.<sup>[12]</sup> It was developed to identify patient experiences and problems with specific health care settings. It is used to measure aspects of care related to information and education to the parent/child, coordination of care, physical comfort, emotional support, respect for patient's preferences, involvement of family, continuity and transition as well as overall impression of quality of care.<sup>[13]</sup> The modifications that were made included introductory and filter questions in relation to structures and processes of care according to Avedis Donabedian model. Quality of care was measured by asking the participants about their perception in regard to satisfaction with the care services they received.

## Results

The findings of the study are interpreted and presented based on the quantitative and qualitative data collected from 107 respondents (parents) and two FGDs.

### *Parent's sociodemographic characteristics*

The mean age of the respondents was 33 years. About half, i.e., 53 (49.5%) of respondents were aged between 30 and 39 years followed by 36 (33.6%) who were aged between 20 and 29 years. Those aged 40 years and above were 18 (16.8%). Majority 88 (82.2%) of the respondents were females. More than half 59 (55.1%) were rural inhabitants, whereas 45 (42.1%) were urban residents. Majority of the respondents 78 (72.9%) were married, and 68 (63.8%) were protestants. Out of the 107 respondents, 8 (7.5%) had never attended school, whereas those who had attained primary, secondary, and college/university level of education were 40 (37.4%), 28 (26.2%), and 31 (29.0%), respectively. The highest percentage of the respondents 42 (39.3%) were casual workers. The above sociodemographic characteristics are shown in Table 1.

### *Children's demographic characteristics*

The mean ( $\pm$ SD) age of the children was 6.9 ( $\pm$ 3.2) years. The age group 0 - 3 years were 19 (17.8%). The children aged 4-6 years were 34 (31.8%) and those aged 7-9 years and 10-13 years were 27 (25.2%) each. The highest percentage of the children 44 (41.1%) had been hospitalized for a period of 1-2 weeks. Majority of the children 64 (59.8%) had history of hospitalization in the past while 43 (40.2%) of the children had not been hospitalized in the past [Table 2].

**Table 1: Parents' sociodemographic characteristics**

Characteristics	Frequency (n=107) (%)
Mean age (±SD)	33.0 (±6.8)
Age (years)	
20-29	36 (33.6)
30-39	53 (49.5)
40 and above	18 (16.8)
Gender	
Male	19 (17.8)
Female	88 (82.2)
Residence	
Urban	45 (42.1)
Semi-urban	3 (2.8)
Rural	59 (55.1)
Level of education attained	
Never attended	8 (7.5)
Primary	40 (37.4)
Secondary	28 (26.2)
College/university	31 (29.0)
Marital status	
Never married	25 (23.4)
Married	78 (72.9)
Divorced	2 (1.9)
Widowed	2 (1.9)
Religious affiliation	
Protestant	68 (63.6)
Catholic	31 (29.0)
Muslim	5 (4.7)
Others	3 (2.8)
Occupation	
Professional	21 (19.6)
Businessperson	30 (28.0)
Casual worker	42 (39.3)
Farmer	14 (13.1)
Income level (Ksh.)	
<5000	25 (23.4)
5000-9000	44 (41.1)
10,000-15,000	20 (18.7)
15,000 and above	18 (16.8)

SD: Standard deviation

### Parents' sociodemographic characteristics and overall satisfaction with care services

Male respondents were significantly more satisfied with the overall care services 15 (78.9%) (odds ratio [OR] = 3.27; 95% confidence interval [CI] = 1.01–10.64;  $P = 0.041$ ) compared to female respondents 47 (53.4%). There was a statistically significant relationship between overall satisfaction with care services and residence of the respondents. Rural residents were significantly more satisfied with the overall childhood cancer care services 41 (69.5%) (OR = 2.85; 95% CI = 1.27–6.39;  $P = 0.011$ ) than urban residents 20 (44.4%). There was also statistically increased proportion of satisfaction among parents who did not

**Table 2: Demographic characteristics of the children**

Variables	Frequency (n=107) (%)
Mean age (±SD)	6.9 (±3.2)
Age (years)	
0-3	19 (17.8)
4-6	34 (31.8)
7-9	27 (25.2)
10-12	27 (25.2)
Period of child's hospitalization (weeks)	
1-2	44 (41.1)
3-4	22 (20.6)
5-6	29 (27.1)
7-8	10 (9.3)
>8	2 (1.9)
Child's past hospitalization history	
Yes	64 (59.8)
No	43 (40.2)

SD: Standard deviation

have past hospitalization history for their children 31 (72.1%) (OR = 2.75; 95% CI = 1.20–6.29;  $P = 0.017$ ) compared to those who had past hospitalization history 31 (48.4%).

### Parents' satisfaction with the ward environment

Descriptive analysis of parents' perception towards the infrastructure/environment on six statements is presented in Table 3. The table shows that majority of the participants were satisfied with all of the statements. Most of the respondents 92 (86%), 89 (83.2%), 88 (82.2%), 83 (77.6%) were satisfied with cleanliness of the wards, size of the bed, ventilation and wash room facilities respectively. Even though 69 (64.5%) were satisfied with the space in the ward and 64 (59.8%) were satisfied with availability of play facilities, a considerable number of respondents 38 (35.5%) and 43 (40.2%) were not satisfied with the above respectively.

Some of the FGD participants stated as follows:

*"A patient has rights while in the ward such as being treated well and sleeping in a comfortable place, sleeping is a problem because of patients' congestion in the ward"* (FGD 1, Participant 1).

*"Services such as availing of hot water in the shower room for the children need to be provided"* (FGD 1, Participant 3).

### Parents' satisfaction with availability of resources for cancer treatment

Among the respondents, 65 (60.7%) reported to be satisfied with the quality of meals provided in the hospital. Sixty-eight (63.6%) respondents were satisfied with the availability of linen. About two-third of the respondents 66 (61.7%) reported that the investigations

required for the children were done on time after they were requested for. However, 41 (38.3%) of the respondents reported that the investigations were not done on time after they were requested for. Sixty-three respondents comprising 58.9% reported that the investigation results were availed on time, whereas 44 (41.1%) of the respondents reported delay in delivery of results. In regard to the availability of doctors, 69 (64.5%) of the respondents reported that the doctors were available whenever needed by the patients. However, 38 (35.5%) of the respondents reported that the doctors were not available when needed. Eighty-one (75.7%) of the respondents reported that the nurses were available whenever needed. However, 26 (24.3%) of the respondents reported that the nurses were unavailable to them whenever needed. Children who had received chemotherapy were 74 (69.2%) and 63 (85.1%) of the respondents reported that chemotherapy drugs were available, whereas 11 (14.9%) respondents reported that chemotherapy drugs were not available. For the children who had received radiotherapy treatment 59 (55.1%), 33 (55.9%) were satisfied with the treatment, whereas 26 (44.1%) were not satisfied. The children who had ever received blood/blood products transfusion were 63 (58.9%). Respondents who reported satisfaction with availability of blood were 47 (74.6%), whereas 16 (25.4) were not satisfied with availability of blood. Children who had experienced pain were 60 (56.1%)

and 59 (98.3%) respondents reported availability of pain relieving medication [Table 4].

Some of the FGD respondents stated as follows:

*"Since I came on admission, I have been told the chemotherapy drug is not available. That is what is delaying me"* (FGD 2, Participant 6).

*"Sometimes, we miss drugs and are told to buy and the drugs are very expensive. For example, one of the parents was told to buy the drug and its cost was fifteen thousand shillings. The issue of availability of chemotherapy drugs needs to be looked at. For example, if my child is supposed to get chemotherapy today and you tell me to buy the drugs and I don't have money, time elapses, and the child delays to get the treatment"* (FGD 2, Participant 3).

*"We appeal to the government to consider children with cancer because they have great challenges. For example, like now the radiotherapy machine has broken down and if one is told to go home and arrange for radiotherapy treatment in a private hospital, it is just like the child is being condemned to die"* (FGD 2, Participant 4).

*"Sometimes chemotherapy treatment is delayed due to unavailability of blood. My child has twice not received treatment on time due to delay as a result of unavailability of blood"* (FGD 2, Participant 6).

*"A child can stay for about a month before being given chemotherapy due to unavailability of blood. This prevents children from getting good care"* (FGD 2, Participant 1).

*"Investigation results for computer tomography (CT) scan take a very long time to be availed"* (FGD 1, Participant 2).

**Table 3: Parents' satisfaction with the ward environment**

Statement	n=107, n (%)	
	Yes	No
Satisfied with the space in the ward	69 (64.5)	38 (35.5)
Satisfied with the cleanliness of the ward	92 (86.0)	15 (14.0)
Satisfied with the size of the bed/cot for the child	89 (83.2)	18 (16.8)
Satisfied with the ventilation of the ward	88 (82.2)	19 (17.8)
Satisfied with the wash room facilities	83 (77.6)	24 (22.4)
Satisfied with availability of play facilities for the child	64 (59.8)	43 (40.2)

**Table 4: Parents' satisfaction with availability of resources**

Statement	n=107, n (%)	
	Yes	No
Satisfied with the hospital meals provided	65 (60.7)	42 (39.3)
Satisfied with availability of linen	68 (63.7)	39 (36.4)
Investigations required for the child done on time after they are requested for	66 (61.7)	41 (38.3)
Investigation results for the child availed on time	63 (58.9)	44 (41.1)
Satisfied with availability of doctors when needed	69 (64.5)	38 (35.5)
Satisfied with availability of nurses when needed	81 (75.7)	26 (24.3)
Availability of chemotherapy drugs (n=74)	63 (85.1)	11 (14.9)
Satisfied with radiotherapy treatment (n=59)	33 (55.9)	26 (44.1)
Satisfied with availability of blood/blood products (n=63)	47 (74.6)	16 (25.4)
Availability of pain relieving medication (n=60)	59 (98.3)	1 (1.7)

### Parents' satisfaction with care delivery processes

Table 5 shows that more than half of the parents did not have any information about their child's illness and type of treatment. Many parents were happy with the response given by the doctors and nurses in regard to their questions and concerns. Many parents were satisfied with their involvement in decision-making regarding the child's treatment as well as the explanation from the nurses and doctors about any procedure and tests done on the children. Many parents reported that they were satisfied with the communication between them and the doctors and nurses.

### Level of parents' satisfaction with care delivery processes

The overall score of parents' perception on care delivery processes was assessed using the eight statements presented in Table 5. Responses that indicate in-sufficient care delivery process were recorded as value "0" and sufficient care delivery process were given a value of "1." This means that the score 1 represented the option "yes," whereas score 0 represented the option "no." The overall score was generated by aggregating the scores. The maximum attainable total score was 8. The mean score was 5.1 and scores above 5.1 were considered as sufficient care delivery

processes and below 5.1 were considered as in-sufficient care delivery processes. More than half 58 (54.2%) of the respondents scored in-sufficient care delivery processes.

### Parents' satisfaction with care providers

Many parents reported satisfaction with the caring attitude and friendliness of the doctors and nurses. About half of the parents were happy with the politeness of the doctors and nurses. Many parents also felt the doctors and nurses were honest and respected their values and beliefs as shown in Table 6.

### Parents' knowledge about their children's care

Table 7 shows that about two thirds of the parents were aware of the side effects of their children's treatment. Many parents were satisfied with the fact that they had been advised on the types of food that their children needed to take. More than half of the parents reported that they had inadequate information about their children's illness and treatment and therefore they would like to know more. Half of the parents said that they were counseled in relation to their children's illness and treatment. Some respondents from the FGDs indicated that they had inadequate information about their children's illness and treatment and would like to know more about their children's illness, type of treatment, and side effects. They stated as follows:

*"My child is getting treatment for cancer though I do not know which kind of cancer it is and I would like to know"* (FGD 2, Participant 2).

*"When a child has been found to have cancer and is required to be given chemotherapy or radiotherapy, it would be good for the health care providers to counsel the parent about the side effects of treatment. There are side effects that children get and this makes one (parent) to think that the end has come. Parents need to be counseled on what to expect so that they don't panic much"* (FGD 1, Participant 5).

*"After the doctor knows it is cancer, it is important for the parent to be told the treatment, whether the child will begin with chemotherapy or radiotherapy and what is expected after radiotherapy. I feel they need to counsel the parent"* (FGD 1, Participant 4).

*"We have inadequate information about our children's illness and treatment so we need to be informed more concerning our children's illness and treatment"* (FGD 1, Participant 6).

*"We need to know the stage of the disease, the duration of the treatment, and the effects of the treatment"* (FGD 2, Participant 4).

Many participants were not aware of the existence of any support group related to the child's illness and they reported that they would like to be involved in the activities of support groups. Some participants from the FGD stated as follows:

Table 5: Parents' satisfaction with care delivery processes

Statement	n = 107, n (%)	
	Yes	No
Information about the child's illness and type of treatment	43 (40.2)	64 (59.8)
Satisfied with the information provided about the child's illness and type of treatment (n=43)	17 (39.5)	26 (60.5)
Satisfied with the response of the doctors to the parents' questions and concerns	76 (71)	31 (29)
Satisfied with the response of the nurses to the parents' questions and concerns	72 (67.3)	35 (32.7)
Satisfied with the involvement in decision making and care of the child	69 (64.5)	38 (35.5)
Satisfied with the explanation from the nurses/ doctors about any procedure and test done on the child	79 (73.8)	28 (26.2)
Satisfied with the doctor-parent/child communication	69 (64.5)	38 (35.5)
Satisfied with the nurse-parent/child communication	76 (71.0)	31 (29)

Table 6: Parents' satisfaction with care providers

Statement	n = 107, n (%)	
	Yes	Yes
Satisfied with the caring attitude of the doctors	71 (66.4)	36 (33.6)
Satisfied with the friendliness of the doctors	70 (65.4)	37 (34.6)
Satisfied with the politeness of the doctors	65 (60.7)	42 (39.3)
Satisfied with the honesty of the doctors	78 (72.9)	29 (27.1)
Satisfied with the respect for parent's values and beliefs by the doctors	80 (74.8)	27 (25.2)
Satisfied with the caring attitude of the nurses	76 (71)	31 (29)
Satisfied with the friendliness of the nurses	70 (65.4)	37 (34.6)
Satisfied with the politeness of the nurses	66 (61.7)	41 (38.3)
Satisfied with the honesty of the nurses	73 (68.2)	34 (31.8)
Satisfied with the respect for parent's values and beliefs by the nurses	82 (76.6)	25 (23.4)

Table 7: Parents' knowledge about their children's care

Statement	n = 107, n (%)	
	Yes	No
Aware of the side effects of the child's type of treatment	75 (70.1)	32 (29.9)
Advised on the type of food the child needs to take	83 (77.6)	24 (22.4)
More information parent would like to know about the child's illness and treatment	70 (65.4)	37 (34.6)
Parent's counseling support in relation to the child's illness and treatment	58 (54.2)	49 (45.8)
Parent's awareness of any support group related to the child's illness	12 (11.7)	95 (88.3)
Do you think you require to be involved in a support group	81 (75.8)	26 (24.2)

*"Involving us in the groups would provide us and our children encouragement and psychological support, we would be educated about cancer and our children's nutritional care needs"* (FGD 1, Participant 1).

*"If parents of children with cancer can have a support group, it can be of help"* (FGD 2, Participant 3).

## Discussion

Findings of the study show that the respondents were moderately satisfied with the overall care their children received in regard to the ward environment, resources for cancer treatment, care delivery processes, service providers, and parents' knowledge about their child's care.

### *Overall satisfaction with the care services provided*

Sixty-two (57.9%) of the parents reported satisfaction with the overall care their children had received and were willing to recommend care services at the hospital to others. However, 45 (42.1%) of the parents reported dissatisfaction with the overall care they had received and were unwilling to recommend care services to others.

The determinants of overall satisfaction with the care in this study were found to be related to the resources for cancer treatment (OR = 3.10; 95% CI = 1.39–6.90;  $P = 0.005$ ), care delivery processes (OR = 2.87; 95% CI = 1.28–6.43;  $P = 0.009$ ), and infrastructure/environment (OR = 2.59; 95% CI = 1.17–5.74;  $P = 0.018$ ). As expected, there is more satisfaction if resources are adequate, care delivery processes are good, and the infrastructure/environment is satisfactory. Similarly, literature also identifies determinants of perceptions of quality of cancer care to be associated to structures and processes of care within a health care institution. Past studies have shown that clinical service delivery, availability of drugs, lack of clear instructions to parents, and amenities provided for parents and children contributes greatly to parents' perception of care.<sup>[11]</sup> In order to provide quality care to patients and achieve high customer satisfaction care ratings, it is therefore important for health care facilities to align the care delivery processes to the patients'/customers' requirements

### *Parents' satisfaction with the ward environment*

The parents and sick children require a comfortable environment in order to facilitate their care and treatment. About 40.2% of the respondents were dissatisfied with the ward environment. This was attributed to congestion, cleanliness, essential amenities, and availability of play facilities. A comfortable environment can contribute to patients' satisfaction with the care given. Other study findings have shown that parents' positive perception is related to their satisfaction with amenities provided.<sup>[11]</sup>

### *Parents' satisfaction with availability of resources*

Study findings show that parents' positive perception is related to their satisfaction with availability of drugs.<sup>[11]</sup> Findings in this study which indicate parents' dissatisfaction with the unavailability of drugs is consistent with other studies. Lack of drugs for patients in government

hospitals contributes to clients' perception of low quality of service.<sup>[14]</sup> There is therefore need for the hospital to ensure the availability of the required resources such as chemotherapy drugs that are needed for childhood cancer treatment.

### *Parents' satisfaction with care delivery processes*

Study findings indicate that majority (54.2%) of the parents had a negative perception of care delivery processes. This dissatisfaction was attributed to information provided by the health care givers in regard to the child's illness and treatment, response of the nurses and doctors to the parents' questions and concerns, parents' involvement in decision making and care of the child and their communication with doctors and nurses.

Respondents with negative perception on care delivery processes were significantly more among the age group of 20–29 years ( $P = 0.006$ ). This could be associated to the fact that young parents may not have the required skills and knowledge to provide care to their children and this is likely to affect their decision-making. They therefore require information and guidance to make informed decisions regarding the child's treatment. Study findings indicate that younger parents expressed need for family involvement in treatment decisions, while older parents received and desired to have more input from medical staff members before making the decision.<sup>[15]</sup>

Majority of the parents (59.8%) did not know about their children's illness and treatment. This finding is in agreement with other studies which found out that care givers do not have the required skills and knowledge to provide the necessary care.<sup>[16]</sup> Lack of information about the child's illness and treatment could have an effect on their involvement in the children's care such as monitoring and management of treatment effects and being involved in decision making concerning their children's care. Parents play a great role as care givers of these patients. It is therefore important for them to have the required information in order to be able to effectively take care of these children.

More than half (64.5%) of the parents were satisfied with their involvement in decision-making regarding care of their child. There is a need for greater recognition of the parent as a care giver for the child during the period of stress related to hospitalization. Studies done have found out that increasing parental involvement in the care of children with cancer may improve perceived care quality. Findings from this study further indicate that over 50% of parents of children with cancer would like to be involved more in decision making about the child's care.<sup>[17]</sup> More than half of the respondents (64.5%) were satisfied with the doctor–parent communication, whereas 71% were satisfied with the parent nurse communication. This is low

compared to other study findings indicating parents' 100% satisfaction with physician interaction.<sup>[11]</sup> This indicates that health care giver - parent communication can enhance parents' positive perception of the care given. Therefore, there is a need to encourage communication between the parents and health care givers.

### *Parents' satisfaction with service providers*

More than half (57%) of the parents were satisfied with the health care providers (doctors and nurses), whereas 43% were not satisfied. The reasons for dissatisfaction with health care providers included the lack of a caring attitude, lack of politeness, dishonesty, and disrespect for parents' values and beliefs. There was a significantly high proportion of respondents with low satisfaction in regard to service providers among parents who had stayed in the hospital for 3–4 weeks ( $P = 0.014$ ) and 5 weeks and above ( $P = 0.025$ ). These findings indicate that dissatisfaction with the health service providers was related to the length of stay in hospital.

The findings demonstrate that parents value efficient services as well as a caring attitude and communication between them and the health care givers. This is in agreement with study findings indicating that quality nursing care is regarded as provision of nursing care in a caring as well as a friendly and respectful manner.<sup>[18]</sup> Findings in this study indicate that parents' satisfaction with the honesty of the doctors and nurses was 72.9% and 68.2%, respectively. This indicates that some of the health care providers do not provide honest information to the parents. Health care providers' honesty to the parents regarding information on the child's care is important because it enables parents to make decisions based on the information given to them.

From the study findings, it is noted that parents would like to be given honest information in order to be aware of what is happening to their child. This is very important to them, given the fact that they are the primary care givers of these children. It is important therefore for them to have honest information to enable them practice their care giving role effectively.

### *Parents' knowledge regarding the children's care*

From the study findings, there is no significant association between sociodemographic characteristics and parents' knowledge regarding the children's care. Majority (70.1%) of the parents were aware of the side effects of the child's treatment. Parents' awareness of their children's illness and treatment as well as the treatment effects is of great importance in providing quality care to pediatric oncology patients. Due to the fact that cancer treatment is long term and has various effects on the child and the family, some of which can be devastating, there is a need for the parents

to understand the illness and treatment in detail. This information to the parents can help in treatment compliance and management of side effects related to the cancer treatment. Studies indicate that inadequate communication provided to parents by health care providers can lead to abandonment of treatment.<sup>[19]</sup> Further study findings indicate that about 98% of parents would like to receive more information about the side effects of treatment.<sup>[20]</sup> This is because majority of parents are worried about side effects and would like to receive more information in regard to the side effects of treatment.<sup>[20]</sup> This is in agreement with findings from this study among the FGD participants.

Many parents (75.8%) expressed the need to have a support group that would provide emotional and psychological support to them. This indicates that support for parents of childhood cancer patients is important because through support they are able to cope with the cancer treatment and its effects. Psychological assessment and intervention can reduce parental stress by increasing coping hence reducing children's psychological problems because of correlation of distress in parents and children.<sup>[21]</sup> Psychological and sociological support as well as communication between the health care team and parents of children with cancer determines the perceived quality among the parents.<sup>[22]</sup> Parents therefore require support related to their children's cancer care such as the required information as well as psychological and emotional support. This could help in ensuring that the quality of life of the sick children is at optimal level in order to improve outcomes.

## **Conclusion**

The parents were moderately satisfied with the oncology inpatient care services their children received. This indicates childhood cancer patients did not receive optimal care expected. The gaps identified in service delivery included those related to the availability of the required resources for efficient care delivery and also educational as well as psychosocial needs of the parents. This study's intension was to establish the parents' perception of the quality of pediatric oncology care at the hospital with the aim of identifying areas and priorities for quality improvement as well as helping to inform policies and guidelines. The results were reported to the hospital's and pediatric department's administration as well as the clinicians and nurses. The results are anticipated to bring changes in regard to the care provided to childhood cancer patients. There is need for provision of the required resources by the hospital's management in order to achieve efficient care delivery processes. Enhancement of parent education in regard to information about the child's illness and treatment as



well as psychosocial support is essential. Encouraging often feedback from parents will enable determination of priorities for quality improvement. Future similar surveys are recommended to establish the level of service improvement.

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### Conflicts of interest

There are no conflicts of interest.

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