

# Parent Perceptions of Paediatric Oncology Services at the Eric Williams Medical Sciences Complex, Trinidad and Tobago

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## ABSTRACT

**Objective:** To assess the perceptions of parents of children with cancer and to determine level of satisfaction with the paediatric oncology services at the Eric Williams Medical Sciences Complex (EWMSC).

**Design and Methods:** Parents of children with cancer were surveyed during the period 12–27 October 2009 as part of a wider needs assessment project using a questionnaire designed to obtain information on their perception of medical, physical and psychosocial resources during the family encounter at the EWMSC.

**Results:** Overall, parents expressed a high level of satisfaction with the quality of delivery of medical and pharmaceutical services which were at no direct cost to the patient. Issues of concern included a lack of a structured clinic appointment system, inadequate patient care assistance on the ward for very young patients and the housing of non-oncology patients in the oncology specialty unit. Apart from their child's illness, fear of job and income loss was a major stressor for parents.

**Conclusion:** Medical needs of patients were perceived to be well met, but there was need to address the psychosocial, physical and educational needs of parents.

**Keywords:** Paediatric oncology, parent perceptions, Trinidad and Tobago

# Percepciones de Madres y Padres Sobre los Servicios de Oncología Pediátrica en el Complejo Eric Williams de Ciencias Médicas, en Trinidad y Tobago

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## RESUMEN

**Objetivo:** Evaluar las percepciones de madres y padres de niños con cáncer, y determinar el nivel de satisfacción con los servicios de oncología pediátrica del Complejo Eric Williams de Ciencias Médicas (EWMSC).

**Diseño y métodos:** Se hicieron encuestas a los padres y madres de niños con cáncer, durante el periodo del 12–27 de octubre de 2009, como parte de un proyecto de evaluación de las necesidades. Se diseñó un cuestionario para obtener información acerca de su percepción de los recursos médicos, físicos y psicosociales durante el encuentro de familias en el Complejo Eric Williams de Ciencias Médicas Complejo (EWMSC).

**Resultados:** En general, padres y madres manifestaron un alto nivel de satisfacción con la calidad de los servicios médicos y farmacéuticos sin costo alguno para los pacientes. Los problemas de mayor preocupación incluían la falta de un sistema bien estructurado de citas médicas, atención inadecuada en relación con la asistencia en la sala de los pacientes muy jóvenes, y el alojamiento de los pacientes no oncológicos en la unidad de especialidad de oncología. Aparte de la enfermedad de sus niños, el miedo a perder el trabajo y los ingresos, era una de las causas principales de stress en los padres.

**Conclusión:** Las percepciones daban por bien satisfechas las necesidades de los pacientes, pero apuntaban al imperativo de atender las necesidades psicosociales, físicas y educativas de padres y madres.

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**Palabras claves:** Oncología pediátrica, percepciones de madres y padres, Trinidad y Tobago

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## INTRODUCTION

The twin island Republic of Trinidad and Tobago is situated northeast of Venezuela 10–11 degrees north of the equator and 60–61 degrees west longitude with an area of 5128 square kilometres. The population is 1.3 million, 50.1% females, with 62% of the population under 35 years and 24.7% under 15 years of age. The ethnic composition is 39.6% African, 40.3% East Indian, 18.4% of mixed descent, 0.6% Caucasian and 0.4% Chinese.

For the period 2000–2002, 5222 new cases of cancer were registered and of these, 2694 (52%) were males. Deaths from cancer for the same period were 3596: 1959 males and 1637 females (M:F ratio of 1.2). Compared to the previous 1995–1999 period, the average number of new cases per year increased by 11% and a 35% increase in the average number of deaths per year was recorded. For the new cases, an increase of 14% was noted for males and 8% for females. There were 49 cases of all malignancies in boys and 36 in girls for children 0–14 years old. The three leading cancer sites were blood, kidney and brain. Paediatric oncology is uncommon [28 new cases per year] (1). However, over 75% can be cured with the use of modern chemotherapy, surgery and radiation (2). In Trinidad and Tobago prior to 2001, children with cancer were treated by the general paediatrician in collaboration with the haematologist, surgeon, radiologist and other specialists. As far back as 1994, the Republic's National Health Service Plan mentioned the development of a National Oncology Centre at the Eric Williams Medical Sciences Complex [EWMSC] (3). In 2001, the National Oncology Centre Functional Programme (4) detailed the requirements to support a national oncology programme and a paediatric oncology consultant was appointed at the EWMSC. A core multi-disciplinary oncology team was formed shortly thereafter with the responsibility for sourcing and coordinating client clinical and support services. In 2009, the Just Because Foundation (JBF), a charitable, non-governmental organization, refurbished a ward and certain spaces in the Wendy Fitzwilliam Children's Hospital to accommodate children diagnosed with cancer and their parents. This dedicated space was named the Just Because Foundation Specialty Unit (JBFSU). The goal of the paediatric oncology service is to deliver a more comprehensive, efficient, client friendly and sustainable programme. To achieve this, a holistic approach must be taken to identify and address the various challenges. The objective of this study was to assess users' perceptions of the existing services to inform further development.

## SUBJECTS AND METHODS

Parents of children diagnosed between 2004 and 2009 and who would have been warded periodically since their diagnosis

were selected by convenience sampling. During the study period 12–27 October 2009, there were four in-patients (with parents) at any given time, while an average of 22 out-patients (with parents) were seen each week at clinic.

Information was obtained through face-to-face semi-structured interviews during weekly clinic visits and whilst on the ward. Information was elicited concerning parents' assessment of availability and use of clinical, physical, and psychosocial resources from initial presentation at the EWMSC through diagnosis and treatment. Their experiences with care and support services were also obtained and they were asked to identify strengths and weaknesses associated with these services. Data were analysed using qualitative methods. The study was approved by the Ethics Committee, Faculty of Medical Sciences, The University of the West Indies, St Augustine, Trinidad and Tobago.

## RESULTS

Seventeen of the 22 parents (77%) participated in the study. Parents reported a high level of satisfaction with clinical service delivery and physician-patient interaction (100%), and with information provided to the patient (82%). There was strong agreement that physicians were sympathetic and encouraging during diagnosis and treatment (100%). There was general appreciation of physicians' dedication and commitment to their patients as evidenced by their availability at all stages of care. There was little delay in getting testing and results, reaching a diagnosis, and accessing medical treatment, drugs, social support and all levels of possible comfort. Parents reported an average of two weeks from presentation to EWMSC to receiving a diagnosis as highly acceptable (Table). The high level of quality service and availability of drugs, at no direct cost to the patient, appeared to have surpassed parents' expectation of service from the public health sector. Reported instances of 'stock-outs' of antibiotics or chemotherapy drugs at the hospital pharmacy were rare. Suggestions made with respect to clinical services were to change the administration of chemotherapy from afternoon to morning periods, which would result in less time away from work for the parent and provide an opportunity for observation and dealing with side effects, and to reduce the fasting period for lumbar puncture and bone marrow tests. Parents reported that a lack of a structured appointment system contributed to long waiting periods and also expressed a desire for more comfortable amenities in the clinic waiting area. With respect to ward staff, often parents had no clear idea who was in charge and who to consult when requesting assistance. There were reports of clashes between parents and nursing staff which parents felt stemmed from miscommunication. There was a high degree of satisfaction with the performance of the oncology-trained nursing

Table: Approximate length of time taken from first presentation at EWMSC to a confirmed diagnosis

Diagnosis	Time from Referral by Referring Agent to being Seen at EWMSC		Approximate Interval from First Presentation at EWMSC to Confirmed Diagnosis
	Referring Agent	Referral Time	
Langerhans cell histiocytosis	Paediatrician	< 1 week	1 week <sup>1</sup>
Leukaemia	Health centre	< 1 week	2 weeks
Lymphoblastic leukaemia	Paediatrician	< 1 week	2 weeks
Hepatoblastoma	Paediatrician	1 day	2 weeks
(ALL) Leukaemia	Paediatrician	Unrecorded	1–2 weeks
(ALL) Leukaemia	Health centre	< 1 week	2 weeks
(AML) Leukaemia	Paediatrician	Unrecorded <sup>2</sup>	2 weeks
(ALL) Leukaemia	EWMSC	Emergency	2 weeks
Brain tumour	Paediatrician	Unrecorded	2 weeks
Leukaemia	Paediatrician	Unrecorded	2 weeks
(ALL) Leukaemia	Paediatrician	< 1 week	2 weeks
(AML) Leukaemia	EWMSC	Unrecorded	2.5 weeks
Embryonal rhabdomyosarcoma	EWMSC	Emergency	< 3 weeks
Chest mass	Paediatrician	Unrecorded	1–2 weeks <sup>3</sup>
Eye and brain tumour	General hospital	Unrecorded	Not recorded
Cancer of the kidney	District hospital	Unrecorded	Not recorded
(ALL) Leukaemia	Paediatrician	Unrecorded	Not recorded

Emergency – no referral

<sup>1</sup>Presented with MRI and CT scan already done at private institution

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<sup>3</sup>Previously spent 7.5 months being tested and treated at EWMSC general services

ALL – Acute lymphoblastic leukaemia; AML – Acute myeloid leukaemia;  
EWMSC – Eric Williams Medical Sciences Complex

staff and a desire to see more staff of this calibre. Of the three parents citing limited satisfaction with information provided, one stated that more information on available treatment options was desirable, another commented that it was a stressful time and she had difficulty processing the information and the third had only received preliminary information as her child was still undergoing diagnostic tests. There was a high level of satisfaction (94%) with accommodation in the JBFSU although concerns were expressed about the use of the Unit to house non-oncology paediatric patients. There was overall satisfaction with the amenities provided on the ward for both parents and children except for the poor quality of potable water.

Although many practical considerations were made by the Unit to ensure a supportive and comfortable environment for clients, including recently installed locker storage units for parents, there was a noted lack of assistance by staff for very young children who could not be left unattended when parents were unavailable. Parents reported little interest from children in consuming the food provided by the institution. There was also a lack of understanding of the assignment and use of private rooms in the JBFSU. While the majority of parents knew of one or more of the social support services available to them at the institution, they appeared to rely heavily on the support of family and friends. In addition to the stress of their child's

illness, the fear of job loss resulting in loss of income added to their concern. Other concerns identified were the costs associated with caring for the child even during the hospital stay and the need for transportation assistance for parents.

## DISCUSSION

The importance of needs assessment in providing high quality care is documented (5). In this study, only 17/22 parents were interviewed as their availability and willingness to participate depended heavily on the severity of their children's illnesses and treatment regimen or clinic schedules at that point in time. Findings showed that clinical and medical service needs and expectations were well met. However, physical, psychosocial and educational issues needed to be further addressed. The user's perception of service delivery was highly influenced by five factors: the physicians' interaction with the young patient, the level of information provided to the parent, the manner in which the physicians related to the parent, the level of commitment and dedication to their patient and the efficiency of service delivery. The information provided to the parent, while attesting to the physicians' knowledge and expertise, also served the psychological function of reassuring the parent. The information that parents wanted following diagnosis were related to the clinical course of the cancer and options for treatment including side effects and risks. However, parents acknowledged that they also researched information online. This research served the purpose of further educating them and reaffirmed the physician's knowledge and expertise in managing the disease process. Parents described the efficiency of the service with reference to minimal delay in having relevant tests done, receiving the test results and getting an early diagnosis. Many of the initial blood tests or X-ray results were available within 1–2 days and bone marrow results were available within 1–2 weeks. Tests done during treatment and maintenance therapy were available within two hours. This level of efficiency may not be sustainable as it relied heavily on an informal understanding and goodwill of all departmental personnel involved in the management of the child and was not rooted in hospital process or policy. It is important to note that despite the ready availability of treatment and support services at no direct cost to the patient, there were associated costs of care, both financial and emotional, to the parent. When patients were admitted to the JBFSU, the parents had to purchase bottled water for drinking because of poor quality of the hospital supply from old plumbing that needs to be replaced. Parents also needed to purchase food, diapers and other personal consumables. However, those in dire need would be assisted by the JBF. Children often preferred food purchased by the parent or prepared by the family, friends or the JBF which provided meals free of charge three times per week. On some occasions, drugs would be purchased from a private pharmacy when the hospital's pharmacy was closed for the weekend, public holidays or in the evenings. The costs of transportation to and from the hospital and the unremunerated cost of having family and friends care for siblings at home when parents must visit or

stay at the hospital represented additional hardship. The sacrifice of having to give up employment together with the burden of a shrinking household income further increased the level of stress and anxiety. Psychosocial support is identified as a priority to help parents to develop coping strategies. They also require advice to access possible sources of financial assistance.

The demand on parent's time was identified as a significant challenge. Parents presented to the clinic before their appointed time in order to accommodate their daily routine which resulted in the perceived lack of a structured appointment system. The commuting time from residence to hospital varied from 1–3 hours and the average length of a clinic visit was four hours including an initial waiting period of 45 minutes to see the doctor, a two-hour wait for laboratory results and a further 15–20-minute consultation. To ease the burden of waiting, parents suggested basic creature comforts such as refilling of the water cooler in the waiting area, more toys or activity books for children, comfortable seating and magazines or other reading material for the adults.

With respect to the suggestions for a reduction of the fasting period before certain procedures, the guideline for fasting before a lumbar puncture or a bone marrow aspirate is six hours. Hence, these tests must be done in the morning and treatment scheduled for the afternoon. This information should be clearly communicated to the parents during counselling sessions. There is a clear need for communication on ward policies and procedures with respect to accommodation of non-oncology patients on the ward.

The study clearly highlighted the gaps between parents' perception of the service and that of the service providers. In some instances, the services requested by the parents in the study were already available. It was clear that further development of the oncology service must incorporate psychosocial support and education within the present management structure.

In summary, parents had overall positive experiences with all levels of service within the paediatric oncology service. Clinical services were well delivered and cited as efficient. Gaps in service delivery clearly existed, largely those pertaining to the physical, psychosocial and educational needs of the parent. The gap between parents' perception and that of the service provider must be bridged with the enhancement of patient/parent education and the provision of better psychosocial support.

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