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Participation in an Occupational Therapy Referral Program for Children with Retinoblastoma

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Abstract

Purpose—Because retinoblastoma typically arises at a very young age, children are particularly vulnerable to vision impairment, associated developmental delays, and functional limitations. Limited information is available describing developmental delay and functional limitations in this population, necessitating supportive services including rehabilitation. The aims of this study were to describe the participation of children with newly diagnosed retinoblastoma in an occupational therapy program that identifies children in need of rehabilitation services. We also identify indications for referral to rehabilitation services among children with newly diagnosed retinoblastoma and enumerate the likelihood of these children receiving the recommended services.

Methods—Twenty-two children participated in longitudinal occupational therapy assessments during the first year after diagnosis.

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Conflict of Interest

None of the authors have any conflicts of interest to declare.

Results—We recommended 1 or more types of rehabilitation services for 16 of 22 (72.7%) participants. Twelve of 16 (75%) received services.

Conclusions—The results of this pilot study indicate that implementing a prospective occupational therapy–screening program is feasible and results in identification and initiation of therapy services in some children with retinoblastoma. Developmental screenings and follow-up of children with retinoblastoma is strongly recommended.

Keywords

retinoblastoma; pediatric rehabilitation; occupational therapy; speech therapy; physical therapy

1. Introduction

Retinoblastoma (RB), a malignancy of the eye, originates in retinal cells of one or both eyes [1, 2]. Approximately 300 new cases of RB arise in the USA annually; 63% occur in children younger than 2 years, and 95% occur in children younger than 5 years [4]. Treatment is based on the laterality of the disease, location and size of the tumor(s), anticipated toxicities, and visual prognosis. Five-year survival is excellent (93%); the aims of treatment are long-term survival, disease eradication, and vision preservation [1]. Treatment includes enucleation, chemotherapy, radiotherapy, cryotherapy, laser therapy, or a combination thereof. Approximately 7.5% of children with RB present with 13q-deletion syndrome [2], a chromosomal disorder characterized by dysmorphic features, mental retardation, and growth delay [1, 2, 3].

Because the RB diagnosis is typically made at a very young age, patients are vulnerable to vision impairments, developmental delays, and functional limitations. Little literature exists on functional impairments associated with RB; most studies focus on either the medical aspects of the diagnosis and treatment or the disease's effect in long-term survivors. Recently however, a 2014 study performed serial assessment of the developmental and adaptive functioning of 94 children with RB and reported that although the baseline developmental function in 84 participants without 13q-deletion syndrome was average, longitudinal assessments revealed that performance declined over time [5]. In addition, a large proportion of RB survivors experience long-term morbidity with restrictions in school, work, self-care, physical function, and quality of life [6–8].

Few reports have described interventions to improve limitations and quality of life in children with newly diagnosed RB. One study reported that 48% of young children with RB (aged 6–40 months) were referred for early-intervention services, specifically rehabilitation for visuomotor skills [9]. While the effect of early interventions services has not been studied in children with RB, early intervention has been found to promote feeding and swallowing skills, cognitive development, motor performance and visual skills in children with or at risk for functional impairment [10,11,12,13]. To be most effective, interventions to prevent or remediate developmental delays in this at risk population should occur as early as possible [14]. To insure that children receive necessary interventions, including occupational therapy, the Individuals with Disabilities Education Act mandates early intervention services for young children with visual impairment (IDEA part C) and their families. IDEA 2004

defines visual impairment as “impairment in vision that, even with correction, adversely affects a child’s educational performance. The term includes both partial sight and blindness.”[§300.8(c)(13)].

In this pilot study we describe the feasibility of an occupational therapy (OT) program that identifies young children with newly diagnosed RB in need of rehabilitation services. We also identify indications for referral to rehabilitation services and enumerate the likelihood of these children receiving the recommended services.

2. Materials and Methods

Recruitment

This prospective study was part of a larger institutional protocol (Clinical Trials Registration Number NCT0018688) in which 107 participants were enrolled February 2005–November 2010. A description of that cohort and treatments is presented elsewhere [15, 16]. This pilot study was added as an amendment to the protocol in April 2009; 33 participants were enrolled on the institutional protocol from April 2009 until the protocol was closed in November 2010. All participants were invited to participate in the occupational therapy evaluation program and there was no selection bias based on health status or other factors. The addendum was approved by the Institutional Review Board at St. Jude Children’s Research Hospital, and informed consent obtained from the patients or parents/guardians, as appropriate, and per the institution’s guidelines.

Evaluations

OT evaluations were administered by occupational therapists with training in the study procedures and assessments. A baseline evaluation visit occurred at diagnosis with follow up evaluation visits at 6 and 12 months after diagnosis. Recommendations for rehabilitation services were made by the evaluating occupational therapist based on the participant’s individual results. At the 6- and 12-month visits, parents/guardians reported any rehabilitation services their child was receiving, including the type (OT, physical therapy, speech therapy, developmental therapy, or services from a teacher of students with visual impairment) and frequency of services (1–2 times per week, 2–3 times per month, or based on consultative need). This data was also used to describe program feasibility, including acceptability and implementation defined by the participant participation rate and the rate of referrals that resulted in the child receiving rehabilitation services. The following demographic data were also obtained: age at diagnosis, unilateral or bilateral involvement, treatment history, audiologic test results, reason for referral (standardized assessment, clinical judgment, or parent/guardian request). Ophthalmology evaluation reports were reviewed to obtain visual acuities. Visual acuities were evaluated in older patients by using Teller acuity cards [17] and in very young infants by their ability to fix and follow or their objection to occlusion of an eye. Vision impairment was classified based on the World Health Organization’s levels of visual function. If vision in the better eye with best-possible glasses correction was 20/50 or better, impairment was classified as mild or no visual impairment; 20/60–20/200, moderate impairment; and 20/200 or worse, severe impairment [18].

Occupational Therapy Assessments

The Battelle Developmental Inventory 2nd Edition (BDI-2) was used to assess developmental skills at diagnosis at the baseline evaluation visit and 12 months later [19]. The BDI-2 assesses 5 major skill domains: adaptive, personal social, communication, motor, and cognitive. The BDI-2 is reliable and valid for use in children (0–7 years) with typical development or severe disabilities, including visual impairment [19, 20]. Norm-referenced scores (scaled scores with a mean of 10, SD = 3) are provided for each subdomain. The subdomain scores combine to form the five BDI-2 Domain scores and the overall DBI-2 Developmental Quotient (each with a standard score mean of 100, SD = 15). Test-retest reliability exceeds 0.80 for the total and all domain scores, and the internal-consistency coefficients range from 0.98 to 0.99. The BDI-2 is widely used in determining children's eligibility for early intervention services because it covers a wider age range than many other tests and assesses the 5 domains of development required by The Individuals with Disabilities Education Act (part C) [21, 22].

The Infant Toddler Sensory Profile was completed by parents 6 months after diagnosis to measure participants' sensory-processing abilities [23]. This tool captures behavioral responses to various sensory stimuli during early daily life (0–3 years); abnormal responses can be barriers to functional performance. The Profile's categories include Low Registration, Sensory Seeking, Sensory Sensitivity, Sensation Avoiding, Low Threshold, Auditory Processing, Visual Processing, Tactile Processing, Vestibular Processing, and Oral Processing. Each category score is compared to that of normally developing children from a standardized sample: typical performance (>16th percentile), probable difference or at-risk (2nd–16th percentile), and definite difference (<2nd percentile).

Statistical Analyses

Descriptive statistics were used to characterize the participants and describe the therapist's referral pattern for rehabilitative services. The non parametric Wilcoxon Rank Sum test was used to compare the median BDI-2 Total Developmental Quotient scores between participants with services recommended and those without services recommended at baseline and at 12 month follow up evaluations specifically. Wilcoxon Rank Sum test was also used to compare the change of BDI-2 Total Developmental Quotient from baseline to 12 month follow up between participants who received services and those who did not receive services. Descriptive statistics were used to assess scores on the Infant Toddler Sensory Profile. All data were analyzed using SAS version 9.3 [24].

3. Results

Thirty-one of the 33 participants to whom the occupational therapy evaluations were offered were enrolled; 1 family declined, and 1 participant was removed from the protocol by the medical team. Twenty-two patients (aged 0–34 months) completed all of the required OT assessments, a 71% participation rate. Of those who did not participate, 5 were lost to follow-up, and 4 were unable to complete the assessments due to scheduling or behavioral issues. The demographic characteristics of the 22 participants and the 9 who did not complete the assessments (referred to hereafter as “nonparticipants”) are presented in Table

1. Nonparticipants tended to have unilateral disease and were approximately twice as old as participants at the time of enrollment. Participants were more likely to have bilateral disease and be treated with chemotherapy and focal therapies. They were also less likely to undergo enucleation.

Table 2 describes the characteristics of children for whom rehabilitation services were recommended and or received. Sixteen of 22 (72.7%) participants were prescribed rehabilitation services, and 12 received them: 4 received services only from St. Jude Rehabilitation Services while at the hospital for treatment; 6 received services only in their home community; and 2 received services at both places. The average age of participants for whom services were recommended was 7.8 ± 5.7 months, and that of participants who received services was 10.6 ± 8.1 months.

Eight participants were referred for one or more rehabilitation service because their standardized assessments indicated a developmental delay in the areas of sensory processing, motor development, and or communication skills. Six were referred based on the therapist's clinical judgment, and 2 were referred based on parental request. Reasons for referral, other than standardized test scores, included reflux and other feeding-related issues, as well as parental concerns about language acquisition. Fourteen of 16 underwent audiologic testing; none had hearing loss. Of the 5 participants who had 13q-deletion syndrome, 5 were recommended for services based on standardized assessment and 4 received services.

Seven participants were referred at their initial evaluation, 1 at their 6-month evaluation and 8 at their 12-month evaluation. Of the participants who were referred at a 6 or 12-month visit, 4 were referred based on the therapist's clinical judgment; 3, based on standardized scores; and 2, based on parental request.

Physical therapy was recommended for and received by 4 participants. OT services were recommended for 6 participants, and 5 received services. Speech therapy was recommended for 16 participants, and 9 received it. One participant was not referred but received OT services in the home community. Two participants received services additional to those recommended. Both participants with visual impairment were referred for 1 or more rehabilitation service, (teacher of students with visual impairment and OT) but only 1 participant received them.

Battelle Developmental Inventory Results

No significant difference was seen between the median BDI-2 Total Development Quotient scores at the baseline evaluation for participants for whom services were not recommended (96.5) and for whom services were recommended (93.5) ($p = 0.77$). No significant difference was seen between the median BDI-2 Total Developmental Quotient scores at the 12-month evaluation for participants for whom services were not recommended (98.5) and for whom services were recommended (95.5) ($p = 0.46$). Additionally, no significant differences was seen for the change of BID-2 Total Developmental Quotient scores from baseline to 12 month follow-up between participants who received rehabilitation services and participants who did not receive services ($p = 0.54$).

Infant Toddler Sensory Profile Results

Twenty-one parents/guardians completed the Infant Toddler Sensory Profile; 1 did not due to scheduling issues. Three children were classified as typical performance in all 10 domains; 12, probable difference in 1 or more domain; and 6, definite difference in 1 or more domain (Fig. 1). When the probable difference and definite difference classifications were combined as an indicator of sensory-processing differences, 18 (85.7%) participants were rated as having some degree of difference in sensory processing. Atypical behaviors were most prevalent in the areas of Sensory Sensitivity (characterized by distractibility and discomfort caused by intense environmental stimuli) and Sensation Avoiding (characterized by a tendency to become overwhelmed or bothered by sensory stimuli and actively seek out environments that provided limited sensory stimuli). Of the 6 participants who were classified as definite difference in 1 or more areas, 5 received referrals, 4 received services, and 3 had 13q-deletion syndrome.

4. Discussion

This pilot study shows that implementing a prospective OT screening program for children with RB is feasible. The program had a participation rate of 71% and 75% of referrals resulted in a child receiving direct rehabilitation services. We also describe the functional characteristics and rehabilitation needs of children receiving treatment for newly diagnosed RB. Although most of the children in our sample demonstrated average overall developmental skills based on BDI-2 scores, 72.7% were referred for rehabilitation services based on delays and deficits in vision, sensory processing, motor development, communication and language, feeding disorders, or a combination thereof. Of those referred participants, 75% received some type of rehabilitation service.

Our findings support those of Ross et al. [9], who reported that although their sample of children (n=41) with RB under the age of 41 months had normal cognitive and motor development, 48% were referred for intervention services to improve visual motor coordination. Healthy children with visual impairment may also experience limitations in development including motor skills. Houwen et al. [25] found that children (mean age 8years 10months $\pm$ 1year 1month) with visual impairment performed more poorly on subtests of the Movement Assessment Battery for Children including eye hand coordination, balance and catching [26], compared to peers without visual impairment; no differences were found in bimanual coordination or aiming.

Eligibility requirements for early intervention services through IDEA part C vary widely from state to state and based on 2013 data from Rosenberg and colleagues the proportion of infants and toddlers likely to be eligible for Part C services ranges from 2% to 78% across the United States while the proportion of children enrolled in Part C ranges from 1.48% to 6.96% [27]. In our study a favorable 75% of the participants we referred for services received some type of rehabilitation service.

Unique to our investigation, 72.7% of participants were referred for speech therapy, and 62.5% of those children received speech therapy. Reasons for this referral included language or cognitive delay on standardized testing, parental or therapist's concern about language

development, and feeding disorders. Evidence of feeding, swallowing, or language disorders in children with RB is limited; however, swallowing/feeding and communication disorders have been reported in various oncology and hematology diagnostic groups [28]. Some anticancer treatments (e.g., chemotherapy) can cause swallowing/feeding impairment and communication delays. Vincristine and carboplatin are the principal chemotherapeutics used to treat RB. Vincristine can cause vocal cord paralysis in children, though this has not been adequately studied in the RB population [29], and carboplatin is associated with hearing loss [30], though there was no incidence of it in our sample.

In our cohort, 1 of 2 participants with visual impairment received services. Because visual impairment can affect a child's motor abilities, language acquisition, cognitive development, social skills, and emotional and behavioral functioning, interventions to prevent or remediate developmental delays should occur as early as possible [31–33].

Only 6 of the 16 children referred for services were referred at their initial evaluation; the others were referred at the 6 or 12-month evaluation visits. These findings suggest the need for early, ongoing therapy screenings in this vulnerable population because diagnosis and/or treatment-related delays may develop throughout the course of treatment. Recently, a serial assessment of the developmental and adaptive functioning of 94 children with RB reported that although the baseline developmental function in 84 participants without 13q-deletion syndrome was average, longitudinal assessments using the Mullen Scales of Early Learning [34] revealed that performance declined over time [5]. Fine motor skills, visual perception, receptive language, and expressive language skills significantly declined in patients treated with enucleation only.

Limitations

The study's small sample size resulted in difficulty making meaningful comparisons between groups and difficulty generalizing results to our target population. Our study sample had a higher percentage of children with bilateral disease and a disproportionately high percentage with 13q-deletion syndrome. Fewer than 7.5% of children with RB present with 13q-deletion syndrome [2]. High rates of bilateral RB and 13q-deletion syndrome in our sample may indicate a selection bias; the caregivers of these children may be more receptive to rehabilitation services. As a result, we cannot generalize our results to the entire RB population. Information on the frequency of services received by participants was provided by the parent/guardian. This methodology carries the risk of recall bias with the potential for over or under reporting of services received. Also, we followed participants only through their first year post-diagnosis; thus, we do not know if children who were referred for services at their 12-month visit received them. Additionally, because services received in home communities were not standardized, we cannot draw conclusions about their effectiveness.

The BDI-2 is a valid, norm-referenced developmental assessment for children (0–7 years). Thus, it provided continuity across assessments, regardless of the participants' age at diagnosis. Although the BDI-2 effectively assesses general developmental function and several referrals were made based on those scores, it may not have the sensitivity to detect functional deficits in areas such as swallowing. Feeding and swallowing skills were not

empirically evaluated with a standardized assessment; therefore, referrals for an oral motor exam by a speech therapist were reliant on parent/guardian reports of concerns in this area or the OTs clinical judgment.

Conclusions

On the basis of the referral patterns and therapy-related needs identified in this pilot study, we recommend monitoring the developmental and functional abilities of all children with newly diagnosed RB. Because of the risks associated with the diagnosis of RB, surgery, chemotherapy, hospitalization, and visual impairment, we recommend early developmental screening to determine whether there is need for rehabilitation services. Screening should be comprehensive and include assessments of fine motor and visuomotor-integration skills, gross motor skills, spatial orientation, communication/language skills, and swallowing/feeding skills. We recommend the BDI-2 as an overall assessment of developmental function. Administration of supplementary evaluations such as the Sensory Profile or an oral motor exam by an occupational therapist or speech language pathologist are recommended should feeding and swallowing or sensory processing concerns be identified by parent or the medical team. We also recommend that children with normal scores on developmental screening be monitored over the course of treatment and thereafter because issues may emerge later. Because children with 13q-deletion syndrome are most likely to experience developmental delays, we recommend that those patients undergo a comprehensive developmental assessment and that they all be referred for OT, speech therapy, physical therapy, and neurocognitive evaluations. A summary of indicators that indicate a need for a referral to a rehabilitation professional are included in Table 3.

We plan to evaluate a larger cohort of children with RB with the addition of measures that evaluate expressive and receptive language function in more detail and more explicitly identify and describe feeding and swallowing dysfunction. The additional data should support early, ongoing developmental evaluations and rehabilitative services for this population. We will also further elucidate the factors that indicate the need for intervention.

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Fig. 1.

Infant toddler sensory profile classifications. Parents/guardians completed the tool, which assessed 10 sensory domains. Data from the 18 participants who showed deficits in at least 1 domain are shown. (Colours are visible in the online version of the article; <http://dx.doi.org/10.3233/PRM-160372>)

Table 1

Demographic and treatment characteristics

Characteristic	Participants n (%)	Nonparticipants ^a n (%)
Laterality of disease		
<i>Bilateral</i>	13 (59.1)	2 (22.2)
<i>Unilateral</i>	9 (40.9)	7 (77.8)
Mean age $\pm$ SD (months) ^b	10.4 $\pm$ 8.5	20.1 $\pm$ 12.9
Sex		
<i>Female</i>	10 (45.4)	6 (66.7)
<i>Male</i>	12 (54.4)	3 (33.3)
Enucleation	10 (45.5)	8 (88.9)
Radiation therapy	2 (9.1)	2 (22.2)
Chemotherapy	18 (81.8)	5 (55.6)
Focal therapy	14 (63.6)	4 (44.4)
13q-deletion syndrome	5 (22.7)	2 (22.2)
Vision impairment ^c	2 (9.1)	1 (11.1)

^aNonparticipants included 9 children who either did not complete the assessments or were lost to follow-up.

^bMean ages at the time of diagnosis were calculated.

^cVision impairment was based on the World Health Organization's classification system. If the vision in the better eye with the best-possible glasses correction was 20/50 or better, impairment was classified as mild or no visual impairment; 20/60–20/200, moderate impairment; and 20/200 or worse, severe impairment [12].

Table 2

Characteristics of the children for whom rehabilitation services were recommended and/or received

Characteristic	Patients who received recommendations for services (n=16) (%)	Patients who received services ^a (n=12) ^b	Patients who did not receive services (n=5)
Mean age $\pm$ SD (months) ^c	7.8 $\pm$ 5.7	10.6 $\pm$ 8.1	10.1 $\pm$ 9.5
Bilateral Disease (n=13)	11 (84.6)	8	3
Unilateral Disease (n=9)	5 (55.5)	4	1
13q-deletion syndrome (n=5)	5 (100)	4	1
Enucleation (n=10)	6 (60)	4	2
Visual impairment (n=2)	2 (100)	1	1
Hearing impairment ^d (n=0)	0	0	0
Chemotherapy (n=18)	14 (77.7)	10	5
Radiation Therapy (n=2)	2 (100)	1	1
Focal Therapy (n=14)	12 (85.7)	8	4
Therapy Recommended			
<i>Occupational therapy</i>	6	5	1
<i>Physical therapy</i>	4	4	0
<i>Speech therapy</i>	16	9	7
<i>Low-vision therapy</i>	1	1	0

^aData indicate rehabilitation services provided at St. Jude or at the child's home community.^bOne participant was not referred but received occupational therapy services at the home community.^cMean ages at the time of diagnosis were calculated.^dFourteen of 16 participants underwent audiologic testing.

Table 3

Test for change of developmental skills from initial assessment to 12-month follow-up for all 22 participants

Skill Domain	Participants who did not receive services (n=10)				Participants who received services (n=12)				P-value ^a
	Median	Min	Max		Median	Min	Max		
Adaptive	3.5	0	12		0.5	-5	24		0.22
Personal-Social	3.5	-4	14		-0.5	-14	24		0.17
Communication	-3	-9	3		-0.5	-16	18		0.76
Motor	4	-7	16		3.5	-12	28		0.64
Cognitive	1.5	-6	5		2	-6	18		0.57
BDI-2 Total	11	-16	31		0	-38	112		0.57

^aP-values were calculated using the exact Wilcoxon rank sum test.

Table 4

Indicators for a referral of the child with newly diagnosed retinoblastoma for rehabilitation services

•	A developmental delay in the area of cognitive, adaptive (self-help), motor, communication or personal social development as indicated by a standardized assessment such as the BDI-2
•	Feeding and or swallowing issues as reported by a parent or observed by the child's medical team.
•	Atypical sensory behaviors observed or reported by parent/guardian or medical team (distractibility and discomfort caused by intense environmental stimulation or a tendency to become overwhelmed or bothered by sensory stimulation).
•	Vision impairment (20/50 or worse in the better eye with best possible glasses correction)
•	Diagnosis of 13q-deletion syndrome