PEDIATRIC BRAIN TUMORS AMONG URBAN CHILDREN: DISABILITIES AND FAMILY ISSUES

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PURPOSE & GOAL:
Purpose: Examine the non-medical and indirect costs and the psychosocial issues for families in caring for their children with brain tumors.
Goal: Assist healthcare professionals in providing support to families by understanding and anticipating the family issues associated with brain tumor treatment and guide the development of interventions.

FINDINGS:

Family Characteristics
- Total number of survey participants = 40
- Race/Ethnicity: White (75%); Black (23%); Middle Eastern (2%)
- Parents in Household: Two-parent (22%); One-Parent (33%); Parent with Grandparent (11%)
- Residency: Urban (61%); Suburban (21%); out state areas (13%)

Health Insurance Types
- Public: (21%); including Medicaid, MICHild and Children’s Special Health Care Services
- Private: (79%) including employer-sponsored, self-pay

Indirect & Direct Costs Incurred by Families

Percent of Parents Reporting Indirect Costs in Most Recent Month of Treatment: Current or Complete

<table>
<thead>
<tr>
<th>Description</th>
<th>Percent</th>
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</thead>
<tbody>
<tr>
<td>Medical costs</td>
<td>9%</td>
</tr>
<tr>
<td>Dental costs</td>
<td>5%</td>
</tr>
<tr>
<td>Vision costs</td>
<td>3%</td>
</tr>
<tr>
<td>Prescription medication</td>
<td>11%</td>
</tr>
<tr>
<td>Non-medical costs</td>
<td>5%</td>
</tr>
<tr>
<td>Child care</td>
<td>11%</td>
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<tr>
<td>Meals</td>
<td>11%</td>
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<tr>
<td>Transportation costs</td>
<td>11%</td>
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<tr>
<td>Total Direct Costs</td>
<td>43%</td>
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</tbody>
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Key Findings
1. Nearly half of all parents of children receiving treatment had high (≥85th percentile) total PSI scores
2. Parents with lower education levels and lower family income reported higher parental stress
3. Significant indirect costs were reported by parents
4. A majority of children (78%) had disabilities (conditions that limited daily activities and/or school performance) similar to prevalence rates in literature
5. Participants reported the following informal family support: friends or family helped with child care (18.45%); friends or family helped with household matters (22.53%)

IMPLICATIONS:

- Families confront significant indirect costs and psychosocial issues
- Findings illustrate the significance of the public health concern since families caring for children with brain tumors are at risk for financial and family psychosocial problems
- Importance of a safety net to protect at risk families (e.g. State Children’s Health Insurance Program)
- Interventions are needed to support families in coping with multiple stressors

STRENGTHS & LIMITATIONS:

Strengths
- Large multi-disciplinary medical center providing comprehensive care
- Nurse clinician was a member of research team
- Diverse population of families in terms of residence, ethnicity, health insurance status and income

Limitations
- Sample size
- Cross-sectional design
- Recall Bias
- Mix of in-person and telephone interviews

Challenges in a Clinical Setting
- Busy clinic; difficult for the nurse clinician to recruit and interview parents while still carrying on clinic responsibilities
- Frequently insufficient time for parents to complete participation in the study between medical procedures at the clinic
- Follow-up telephone interviews were not always successful

RESEARCH TEAM

- Multidisciplinary Neuro-Oncology Program at Children’s Hospital of Michigan
- Neuro-Oncology Nurse Clinician served as the research assistant
- Wayne State University HIC approval throughout the study

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- Lynnette Essenmacher, Department of Pediatrics