

Introducing Palliative Care for Children with Brain Tumors and Their Families Through an Educational Intervention at the Time of Diagnosis

Clinical Problem

- Pediatric Palliative Care (PC) can help manage symptoms and reduce physical and emotional suffering of children with brain tumors starting at the time of diagnosis and continuing throughout the disease process
- Despite known benefits of PC, children with brain tumors are referred to PC inconsistently, often late in the disease process, and not at the time of diagnosis
- Caregivers of children with brain tumors are unfamiliar with the purpose of PC as supportive care starting at the time of diagnosis. Caregivers have misperceptions regarding the purpose of PC as a result of lack of education at the time of diagnosis

Purpose

To measure whether the caregivers of newly diagnosed children with brain tumors find PC education helpful and whether they are open to PC at the time of diagnosis

Objectives

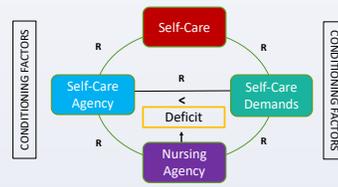
To measure whether caregivers find PC education helpful and whether they are open to PC at the time of diagnosis

Literature Review

- PC is valuable, yet many children do not receive these services. Parents are uncomfortable with the word PC and often confuse the word with "giving up." Education of PC is necessary to clear misperceptions (Kaplan, 2016; Shalev et al., 2018; Spruit, Bell, Toly, & Prince-Paul, 2018).
- Parents of children with cancer perceive PC as end-of-life care, offered only when no curative treatments are available. Parents would be amendable to PC with the correct framing and knowing that PC could be offered along with curative therapy (Haines, Frost, Kane & Rokoske, 2018; Levine et al., 2017).
- Nurse-led patient education is effective. Newly diagnosed families with cancer have specific educational needs (Rodgers, Stegenga, Withycombe, Sachse, & Kelly, 2016; Smith, Sachse, & Perry, 2018).
- Caregivers of children newly diagnosed with brain tumors benefit from PC education at the time of diagnosis (Bradford et al., 2014).

Theory

Dorothea Orem's Theory of Self-Care

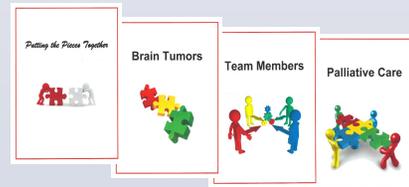


Measures

- Independent Variable: PC Education
 - Dependent Variable: Helpfulness and Openness of caregivers of children newly diagnosed with brain tumors
 - Caregiver Question Worksheet
1. Did you find the education of PC helpful at the time of diagnosis?
 2. Are you open to receiving PC at the time of diagnosis?

Intervention

To introduce Palliative Care and educate caregivers of children with newly diagnosed brain tumors on the components and benefits of Palliative Care using the pediatric Palliative Care Toolkit



Implementation

- Week 1: Neuro-oncology APN will provide a PC educational session within the first week from diagnosis. Caregivers will receive the PC Toolkit
- Neuro-oncology APN will notify PC team for PC consultation
- Week 2: PC APN or physician will provide a PC education session followed by a formal PC consultation
- Week 4: Neuro-oncology APN will perform third PC education followed by administration of Caregiver Questions

Evaluation

Caregiver Question Worksheet

Caregiver Question Worksheet

1. Did you find the education of Palliative Care helpful at the time of diagnosis?
___ Yes ___ No
2. Are you open to receiving Palliative Care at the time of diagnosis?
___ Yes ___ No
3. Additional Comments:

Caregiver 1

Father of a school-aged female newly diagnosed with a low-grade brain tumor post resection. Caregiver responded to the questionnaire:

- Did you find the education of PC helpful at the time of diagnosis? Yes
- Are you open to PC at the time of diagnosis? Yes
- Additional comments included:
 - "The PC Toolkit is super helpful"
 - "Having the information was helpful"

Caregiver 2

Mother of a young adult female newly diagnosed with a low-grade brain tumor post complete resection. Caregiver responded to the questionnaire:

- Did you find the education of PC helpful at the time of diagnosis? Yes
- Are you open to PC at the time of diagnosis? Yes

Caregiver 3

Father of a school-aged female newly diagnosed with a low-grade brain tumor post partial resection. Caregiver responded to the questionnaire:

- Did you find the education of PC helpful at the time of diagnosis? Yes
- Are you open to PC at the time of diagnosis? Yes
- "I did not know my child would have side effects from the treatment."
- "I feel informed and supported."

Caregivers Who Did Not Meet Inclusion Criteria

- 2 Spanish-speaking Caregivers
- Caregiver of child with a spinal cord tumor
- Caregiver did not complete educational session

Discussion

- Three Caregivers of children newly diagnosed with brain tumors were enrolled into the project. The small sample size does not take from the importance of the topic of introducing PC to children at the time of diagnosis
- Caregivers responded positively and were open to the introduction of PC at the time of diagnosis and found the educational intervention helpful
- Project limitations include a small sample size

Significance to Nursing Practice

- Oncology Nurses are well-positioned to advocate for children and caregivers to have access to PC beginning at diagnosis
- Oncology Nurses educate Caregivers about PC in order to clarify misperceptions
- PC Education focuses on the benefits and purpose of PC in addressing physical and psychosocial needs starting at diagnosis
- A PC Toolkit is an effective means to educate families about PC. Written materials reinforce verbal education and serve as a resource for families

Conclusion and Future Considerations

- An educational intervention is an effective means for Caregivers to understand the purpose and benefits of PC at diagnosis
- Caregivers are receptive to education of PC when offered at the time of diagnosis
- Patients will continue to be enrolled into the project. Sustainability of the project in the future includes:
 - Continuation of introducing PC at diagnosis as standard of care for children with brain tumors
 - Inclusion of children with other Central Nervous System tumors and Pediatric Oncology diseases
 - Inclusion of Spanish-speaking Caregivers by developing a Spanish version of the PC Toolkit

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- References available upon request