



Adding a Parent to the Brain Tumor Team:

*Evaluating a Peer Support Intervention for
Parents of Children with Brain Tumors*

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Speaker Disclosure Statement

- Kathy Riley, MPH, CHES, Vice President of Family Support for the Pediatric Brain Tumor Foundation



Instructional Objectives

1. The attendee will describe how parents and professionals collaborate to improve the patient experience in the inpatient and outpatient setting.
2. The attendee will recall the benefits of an effective peer support intervention.
3. The attendee will demonstrate knowledge of key constructs of the Social Support theory.



Why Study a Peer Support Intervention for Pediatric Brain Tumor Families?

- 28,000 children and teens living with the diagnosis (8)
- 4,600 new cases diagnosed annually (3)
- Five-year relative survival rate nearly 75% (4)
- Survivors suffer from lifelong effects (1)
- Pediatric brain tumors leading cause of cancer death in children ages 0-19, surpassing leukemia (2)



PBTF Framework for Family Support

Mission

- Care. Cure. Thrive.

Goal of Family Support Programs

- Provide a robust menu of family support programs and resources to meet their most pressing needs

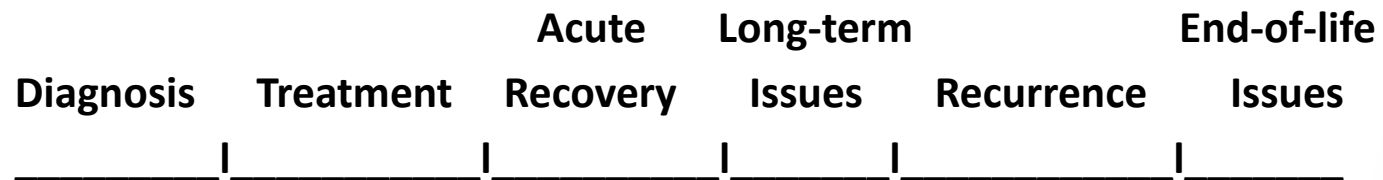
How many need our help?

- **92,000 families** (4,600 patients per year x 20 years)



When Do Families Need Our Support?

Throughout the continuum of care



The Family Voice

Imagine yourself in the shoes of a family member of one of your patients on a particular day in a particular moment.

- Where are you?
- Who are you?
- What do you see?
- What do you hear?
- What do you feel?



Background

Parents/primary caregivers of children diagnosed with brain tumors experience numerous stressors (5)

Social support:

- associated with lower levels of stress (7)
- considered an integral intervention to improve resilience (9)
- defined by ways in which social networks help individuals cope with stressful events
- within chronic disease/cancer literature, social networks were a significant source of emotional and practical support for parents of ill children (6)



Intervention and Study Purpose

PBTF sent a Veteran Parent (VP) to work as part of a neuro-oncology team at a large pediatric hospital.

VP trained through a VP Program designed by founders of a pediatric brain tumor support network.

Describe/quantify impact of a Veteran Parent's (VP) presence in terms of:

- improving resilience in parents
- improving quality of life



Primary Aims

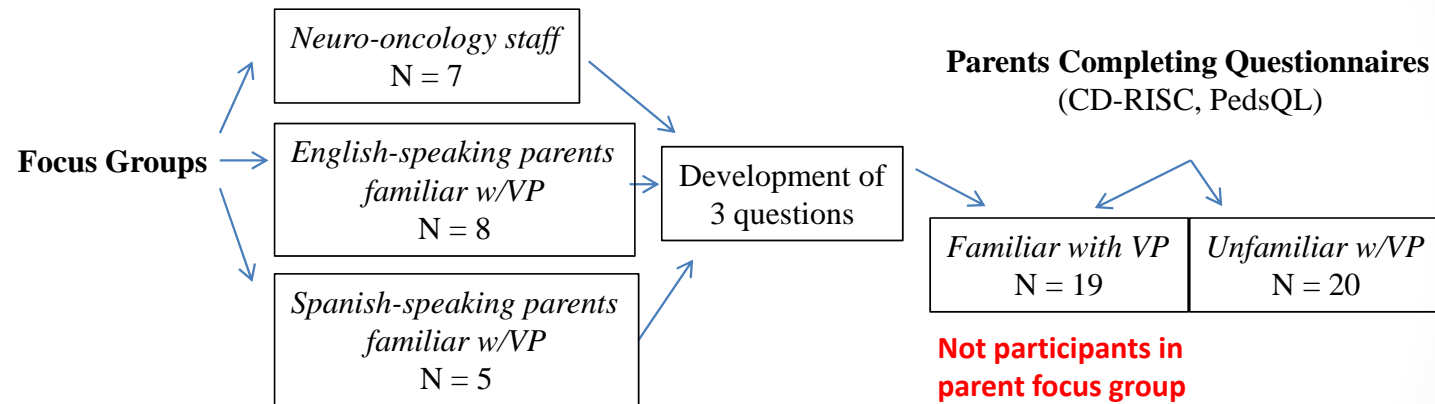
- 1) Quantify number of parents seen and services provided by VP during four-month period
- 2) Engage focus groups of parents and healthcare providers in defining and describing services provided by VP and identify gaps/needs
- 3) Develop parent questionnaire to assess/evaluate parental needs and the services provided by VP
- 4) Determine difference in parental resilience and QOL in parents who met frequently (≥ 5 times) with VP compared with those who did not



Theoretical Framework

- | | |
|---------------------------------|---|
| 1. Emotional Support | Expressions of empathy, faith, love, trust and caring |
| 2. Instrumental Support | Tangible aid and services that others provide |
| 3. Informational Support | Advice, suggestions, and information others provide |
| 4. Appraisal Support | Information that is useful for self-evaluation |
| 5. Gaps | Gaps in support/areas that may be lacking, e.g. financial assistance, transportation and language barriers |

Flow of Study and Recruitment



Methods and Flow of Study

1) Mixed-methods, cross-sectional study utilizing validated tools:

- parental resilience (CD-RISC-25)
- impact of illness on family (PedsQL)

2) Focus groups held:

- Neuro-oncology staff
- English-speaking parents (all familiar w/VP)
- Spanish-speaking parents (all familiar w/VP)

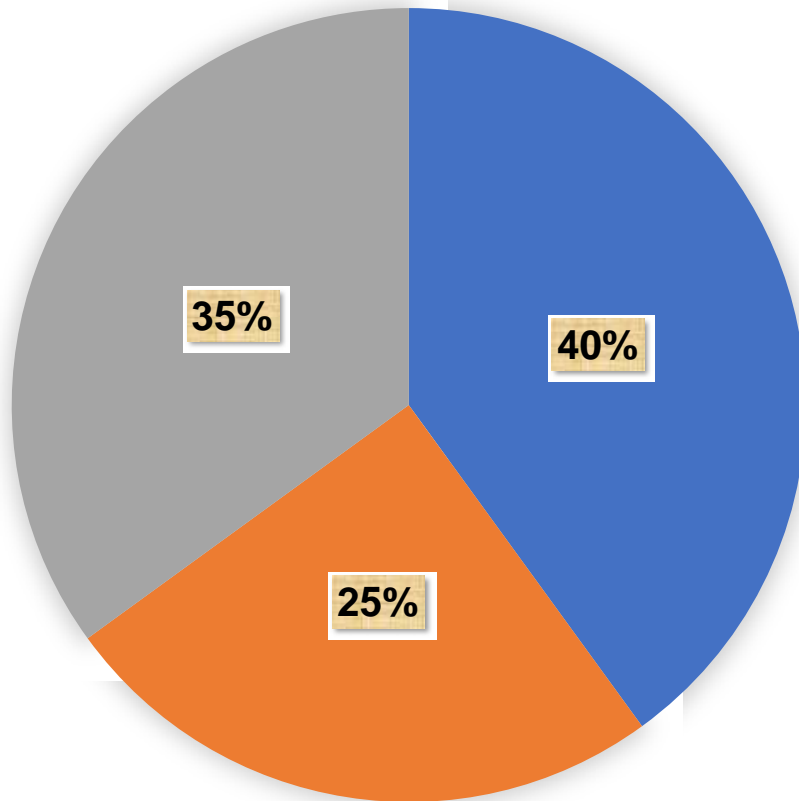


Methods and Flow of Study (cont'd)

- 3) Qualitative data from focus groups transcribed into Atlas.ti. Analyzed using key constructs of social support theory.
- 4) Development of 3 questions
- 5) Parents complete questionnaires (CD-RISC-25 and PedsQL):
 - familiar with VP: N=19 (answer 3 questions)
 - unfamiliar with VP: N=20 (do not answer 3 questions)



Focus Groups



- English-speaking parents (N = 8)
- Spanish-speaking parents (N = 5)
- Staff (N = 7)

Focus Groups

Common themes categorized and coded into 4 constructs:
emotional, instrumental, informational, and appraisal

Three questions developed from focus group for parents exposed to VP:

- 1) How has your interaction with the VP influenced your own interactions?
- 2) When do you feel is the optimal time to meet with the VP for the first time?
- 3) Describe what your brain tumor journey would have been like if you had not met the VP.



Results – Quantitative Data

- Over the course of 16 weeks, the **VP recorded 316 visits** with families.
- No significant differences between the VP and non-VP parent groups in total scores or domain scores on the PedsQL Family Impact module or CD-RISC-25, or individual questions, after correction for multiple comparisons:
 - $P \leq .008$ for PedsQL questions
 - $P \leq .002$ for CD-RISC-25 questions



Results – Qualitative Data

- Most parents (83%) reported VP made a positive difference in terms of:
 - navigating resources
 - receiving emotional support and comfort
 - experiencing reduced isolation
 - better coping
 - greater hope for their child's future
- A majority of parents (92%) expressed a preference for meeting VP as soon as possible after diagnosis.
- Many Spanish language parents described becoming informal VPs themselves, visiting/ providing support to others, without realizing they have done so.



Results – Qualitative Data

Gaps identified by parents and staff:

- ✓ Financial assistance
- ✓ Transportation
- ✓ Language barriers
- ✓ Programs for children/teens
- ✓ Transitioning to adulthood



Results – Qualitative Data

One parent said, “[The VP] understood what we went through and really let me pour my heart out with her.”

Another parent said, “You’re the first person that I really want to talk to because you get what’s going on here.”

A member of the neuro-oncology team said, “There’s nothing like another parent or another soul next to you who’s lived it, understands it, knows what the pain is like.”

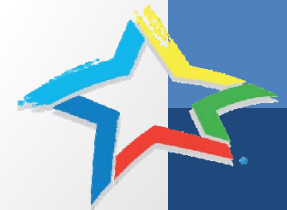


Conclusions

- Adding a VP to the clinical team meets critical psychosocial needs of parents/caregivers.
- Strong preference for meeting the VP early, suggests contact with the newly diagnosed family as soon as possible.
- VP built rapport with Spanish-speaking parents despite not sharing the same racial/ethnic background.
- Full inclusion of a VP on the health care team elevates family-centered care to a new level.



Questions?



Effective Interventions

Work with one or two partners to discuss the following questions:

- What in your experience has worked best to meet the psychosocial needs of the families of pediatric oncology patients?
- What makes the intervention successful?
- How can you imagine putting the findings of this study to use?



Collaboration

Mary Baron Nelson, PhD, RN
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**Pediatric
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