

Palliative Care: Policy Implications for Children with Special Needs

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Presenter Disclosures

William Livingood

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose

Growing Need for Palliative care

- Children with chronic debilitating diseases are living longer, some well into adulthood.
- Without cures, life with a debilitating disease is all these children will ever know.
- Traditional Medical Care tends to emphasize preservation of life.
- Heroic treatment efforts frequently diminish quality of life.
- Policies and 3rd party reimbursement that emphasize quality of life (Hospice care) do not support concurrent reimbursement for treatment.

Palliative versus Hospice Care

Palliative Care

- Quality of Life focus
- Curative Treatment continues
- Continued health care prevention & prevention of opportunistic disease
- May hope for cure, perhaps in distant future

Hospice Care

- Quality of Life focus
- No Curative Treatment allowed
- No preventive health care
- No hope for cure

Community PedsCare: Palliative Care

- Community PedsCare was initiated in 2000
- To address the need for holistic and coordinated care for children with chronic illnesses
- Formed through various alliances of healthcare organizations throughout Northeast Florida, including:
 - Community Hospice of Northeast Florida
 - Baptist Health – Wolfson Children’s Hospital
 - Nemours Children’s Clinic
 - University of Florida, College of Medicine-Jacksonville
 - Jesse Ball duPont Fund

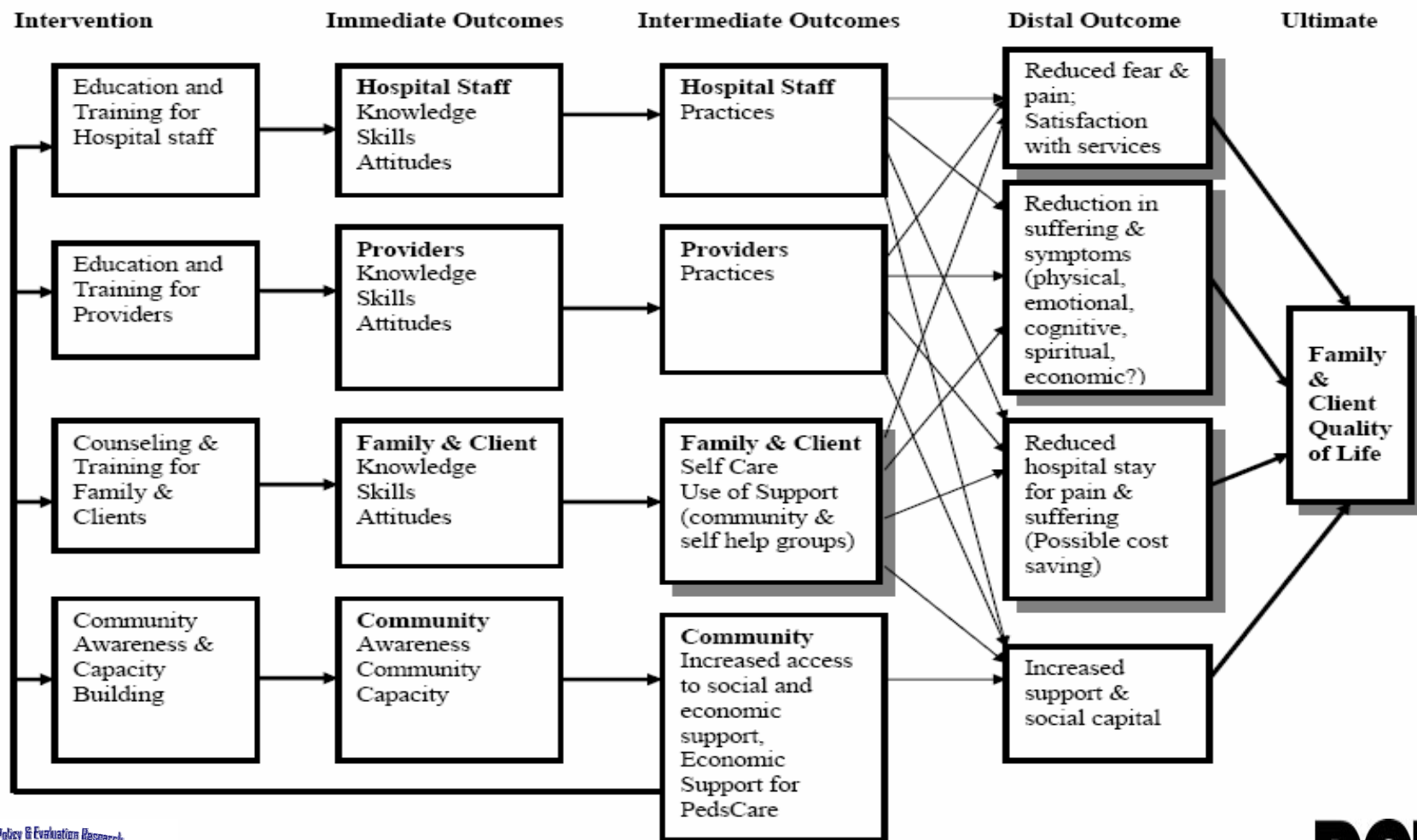
Community PedsCare

Community PedsCare palliative care program provides a multi-disciplinary team approach for children and their families with:

- home nursing assessments,
- psychosocial interventions,
- child life specialist care,
- spiritual support,
- pain and symptom management, and
- volunteer interventions that complement specialized medical care.

Community PedsCare Evaluation Logic Model

Figure 1
Evaluation Logic Model Pediatric Palliative care



Community PedsCare Evaluation

Hypotheses:

- Enrollment in PedsCare will improve Quality of Life (specifically for Family Care Givers)
- Enrollment in PedsCare will reduce hospitalization (as measured by days in hospital)
- Enrollment in PedsCare will reduce the costs of care, (particularly those associated with hospitalization)

IRB Reviews

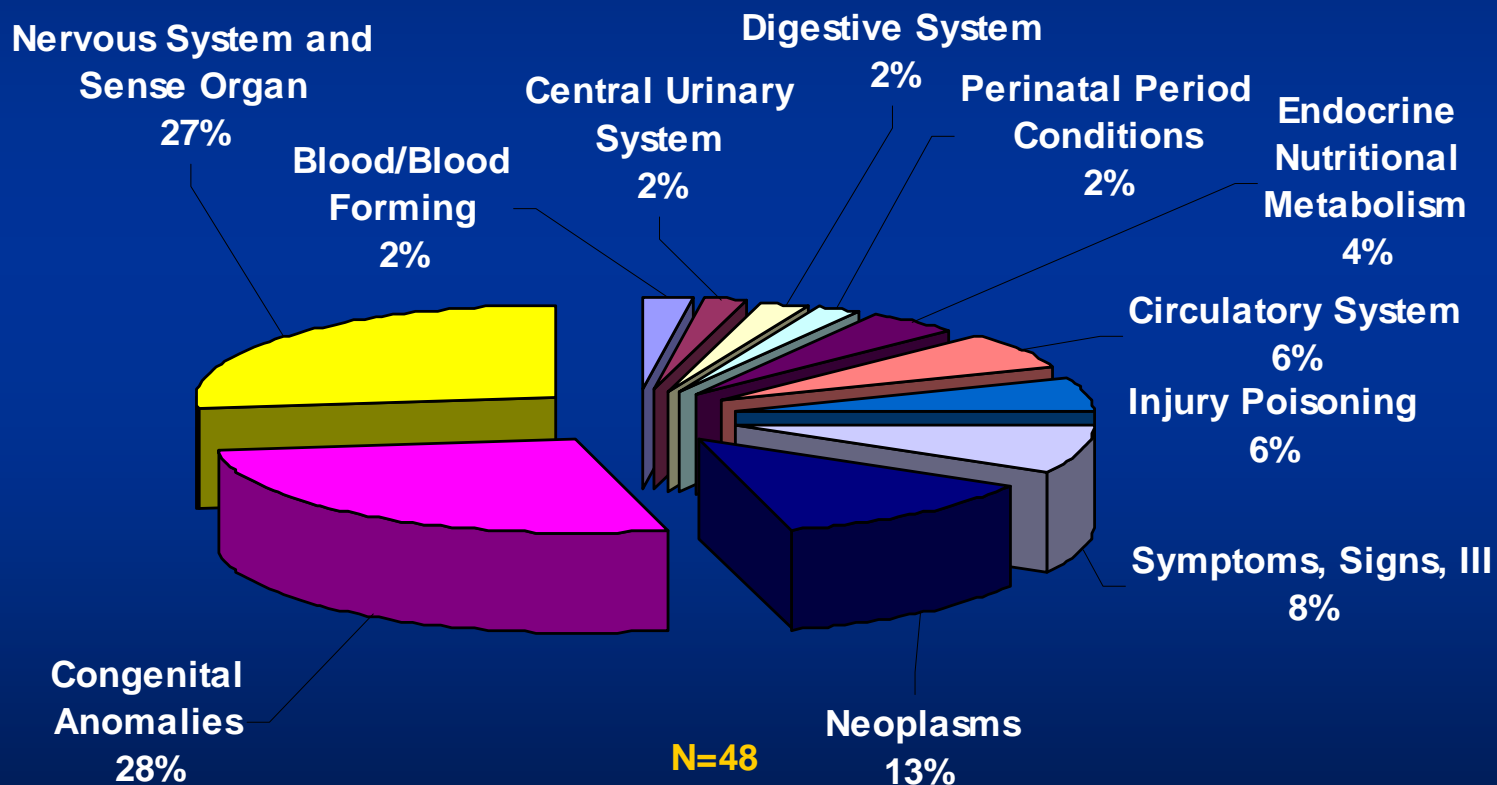
- Florida Department of Health
- University of Florida, College of Medicine-
Jacksonville
- Wolfson Children's Hospital (Baptist
Health)
- Nemours Children's Clinic

Evaluation Design

- Data
 - Cost and Utilization: Secondary data hospital cost and utilization for each client
 - HRQOL: Primary data collection with phone survey of family care givers
- Sample
 - Cost & Utilization: 40 children enrolled in PedsCare over a long enough period to observe pre and post enrollment utilization and costs
 - HRQOL: 53 Family Care givers contacted by phone (76% of 70 eligible with varying periods of PedsCare enrollment)

Variations in Diagnostic Groups

Diagnostic Group of Children Enrolled in Pediatric Palliative Care (Hospitalization 2000-2006)



Hospital Days & Costs Before & After Enrollment

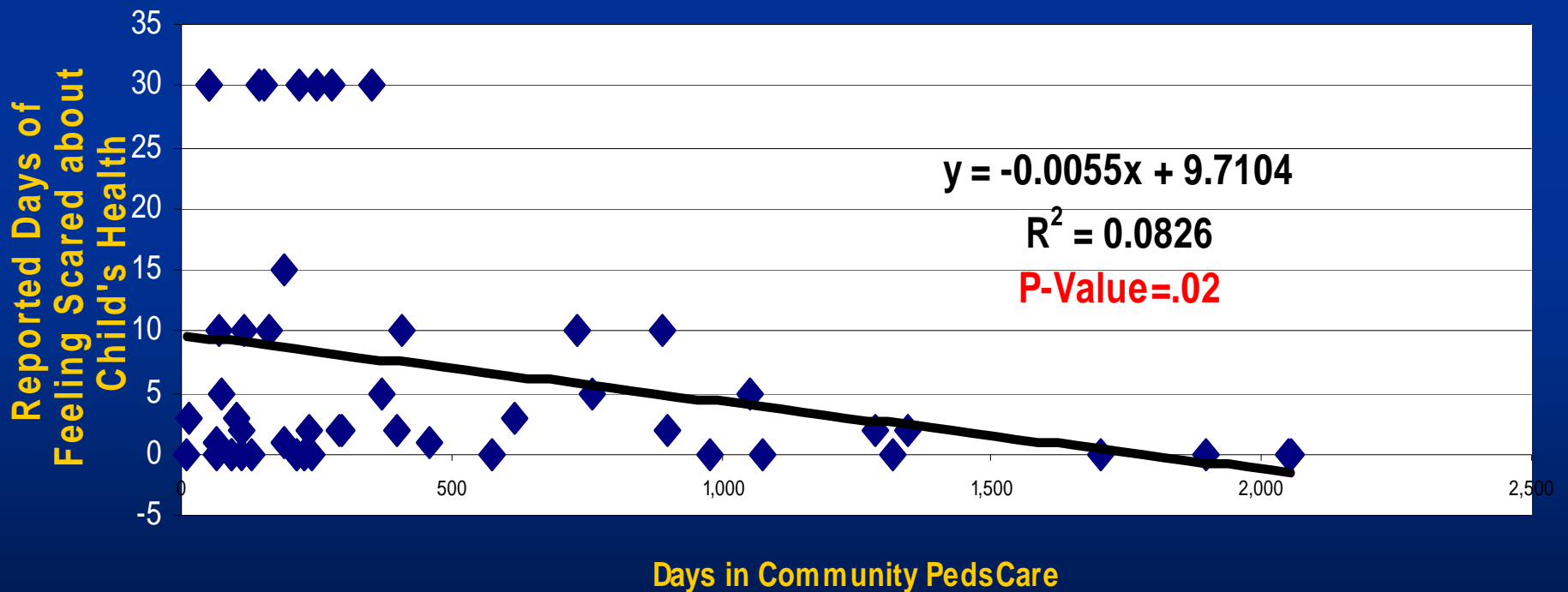
Community PedsCare Client	Before Palliative Care N=40		After Palliative Care N=40		P-value *
	Mean	Standard Error	Mean	Standard Error	
Cost and Utilization Findings					
Hospital days (Days/Quarter)	2.92	.94	1.22	.39	0.03
Total Diagnostic Charges/Quarter	\$2,125.30	918.44	\$1,078.28	430.11	0.13
Total Charges/Quarter	\$7,866.59	2,347.31	\$6,663.52	2,785.22	0.34

*Paired One tailed T-test -Before and After PedsCare

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Impact of Community PedsCare on HRQOL

Relationship of PedsCare period of Enrollment to days of feeling scared about child's health



Limitations of Study

- Small sample size
- Need to factor in negative impact of disease course (degeneration of health), limiting positive impact on utilization, cost savings and health related quality of life.
- No control group: Attempt at using control group failed; ICD 9 codes may not adequately address severity of illness, a major factor in service utilization.
- Dose effect (the amount of time after enrollment required to produce an effect) may need to be determined before impact can be fully assessed.
- The HRQOL survey was developed using multiple local “experts” and families, need to establish more psychometrics.

Conclusions

- Results showed promising decreases in hospital costs and utilization.
- Results showed improvements in key quality of life indicators for families with children with special health care needs.
- Results provide important insights for program and policy development as well as evaluation research design.

Policy Implications

- More studies with multiple sites are needed
- Public and Private payers (insurers) should consider funding palliative care as an essential component of health care for children with debilitating disease.