Symptoms and Quality of Life of Children and Adolescents Receiving Cellular Therapies

Jessica Ward, PhD, MPH, cPNP, RN
Melody Hellsten, DNP, APRN, PPCNP-BC, CHPPN
Kimberly Powers, MA, CPNP, RN
Jilayne Smith, MSN, RN, CPNP-AC
Paula Murray, PhD

Objectives

- To describe symptoms commonly reported by children and adolescents during hematopoietic stem cell transplantation (HSCT) and chimeric antigen receptor (CAR) T-cell therapy.

- To describe health-related quality of life (HRQoL) domains affected during HSCT and CAR T-cell therapy.

- To discuss the relationship between symptoms and QoL of children and adolescents undergoing HSCT and CAR T-cell therapy and the association with parent psychological distress.

Background

- Children and adolescents experience poor HRQoL, distressing symptoms during HSCT.
- Onus of transplant care is placed on parents.
- Ability of parents to care for their sick children is associated with improved outcomes in other clinical settings.

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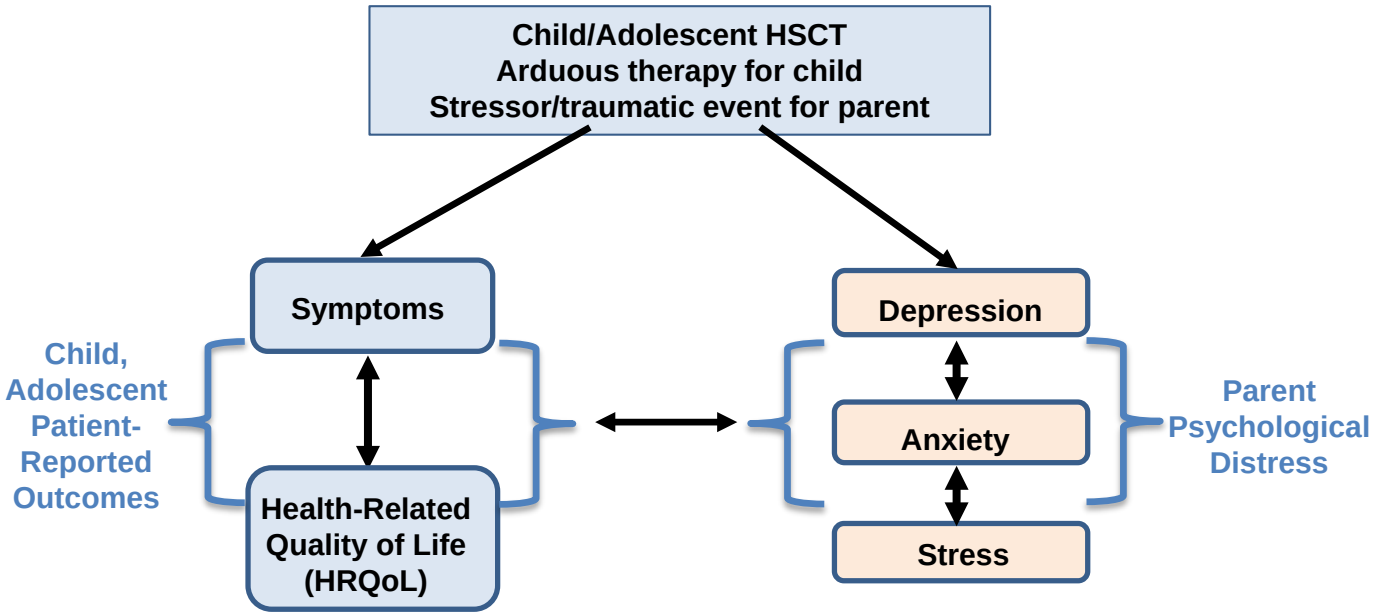
Study Aims

1: To describe the relationship between *symptom burden and HRQoL* in children and adolescents undergoing HSCT or cellular therapy.

2: To describe the association of *parent anxiety, depression, and stress* with the child's symptom burden and HRQoL among children and adolescents undergoing HSCT or cellular therapy.

Study Model

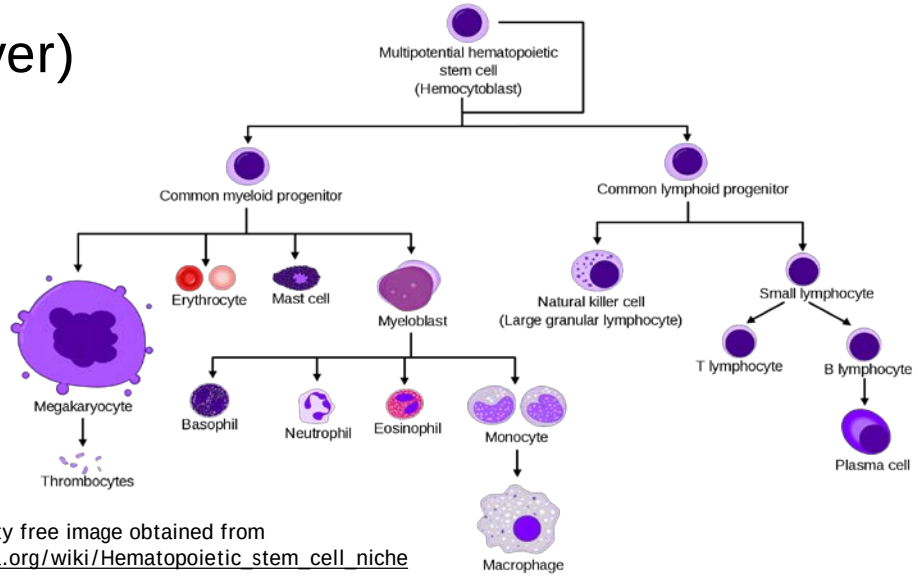

Child/Adolescent HSCT
Arduous therapy for child
Stressor/traumatic event for parent
Symptoms
Health-Related Quality of Life (HRQoL)
Child, Adolescent Patient-Reported Outcomes
Depression
Anxiety
Stress
Parent Psychological Distress

Sites

- Kimberly Powers, MSN, RN, CPNP
  - Ann & Robert H. Lurie Children's Hospital of Chicago
- Melody Hellsten, DNP, RN, PPCNP-BC, CHPPN
  - Texas Children's Hospital
- Jilayne Smith, MSN, RN, CPNP-AC
  - Children's Hospital of Colorado

Inclusion Criteria

- Male and female children, ages 2 to 18 years
- Allogeneic HSCT, autologous HSCT, or CAR T cell therapy
  - Any stem cell source or conditioning regimen
  - Any underlying diagnosis
- One parent per child (primary caregiver)
- English or Spanish-speaking



Royalty free image obtained from
https://en.wikipedia.org/wiki/Hematopoietic_stem_cell_niche

Design

- Longitudinal, prospective cohort, repeated measures
- Accrual goal: 140 parent/child dyads
- Convenience sampling
- Enrollment: Spring 2018 to Winter 2019
- Convenience sampling method
- REDCap® for electronic data collection and data entry
- Participant incentives at each time point

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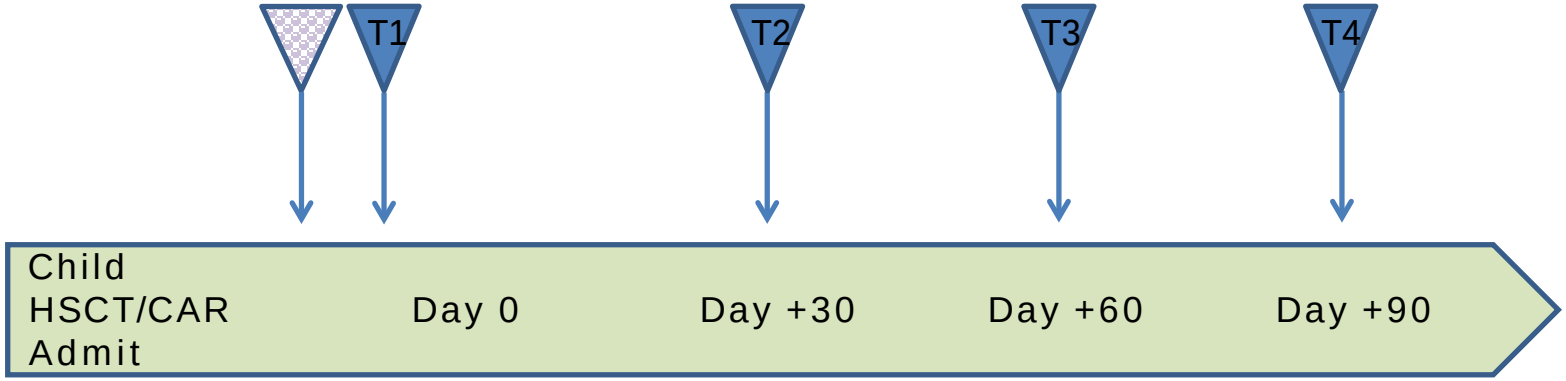
Schema



= Screening, informed consent/assent, baseline evaluation

= Parent (Psychological Distress), Child (Symptoms, HRQoL) Measures

Measures

	Constructs	Measures
Children	Symptom Burden	1. Memorial Symptom Assessment Scale (MSAS)
	HRQoL	2. PedsQL Cancer Module (PedsQL)
Parents	Parent Demographics	3. Background, Health, Lifestyle Questionnaire
	Anxiety	4. Beck Anxiety Inventory-I
	Depression	5. Beck Depression Inventory-II
	Perceived Stress	6. Perceived Stress Scale
	Symptom Proxy	7. MSAS Parent Proxy
	HRQoL Proxy	8. PedsQL Parent Proxy

Sample Characteristics

		Mean ± SD / N (%)
Dyads		140 (100)
Age	Child	8.4 ± 5.0
	Parent	39.0 ± 8.1
Gender - Child	Male	79 (56.4)
	Female	61 (43.6)
Gender – Parent	Male	27 (19.3)
	Female	113 (80.7)
Diagnosis	Malignancy	96 (68.9)
	Red Cell Disorder	14 (10.0)
	Immune Deficiency	9 (6.4)
	Metabolic Disorder	2 (1.4)
	Other	19 (13.6)
Transplant Type	Allogeneic	81 (57.9)
	Autologous	36 (25.7)
	CAR T	23 (16.4)

Health-Related Quality of Life (HRQoL)

Lowest HRQoL Domains Across Age Groups

Pre-HSCT/CAR T	Day +30	Day +60	Day +90
Procedural Anxiety	Procedural Anxiety	Procedural Anxiety	Procedural Anxiety
Nausea	Nausea	Nausea	Communication
Worry	Pain & Hurt	Cognitive Problems	Cognitive Problems

- Child self-reports were used unless patients who were too young to complete the self-report measure (<5 years) OR if an older patient missed a timepoint due to illness
- In general, HRQoL scores were lowest pre-HSCT/CAR T and improved over time.

Most Commonly Reported Symptoms

2 – 6 years

Pre-HSCT/CAR T	Day +30	Day +60	Day +90
Appetite (77%)	Appetite (59%)	Pain (49%)	Appetite (46%)
Nausea (71%)	Nausea (55%)	Nausea (49%)	Pain (38%)
Vomiting (65%)	Energy (53%)	Appetite (47%)	Energy (34%)

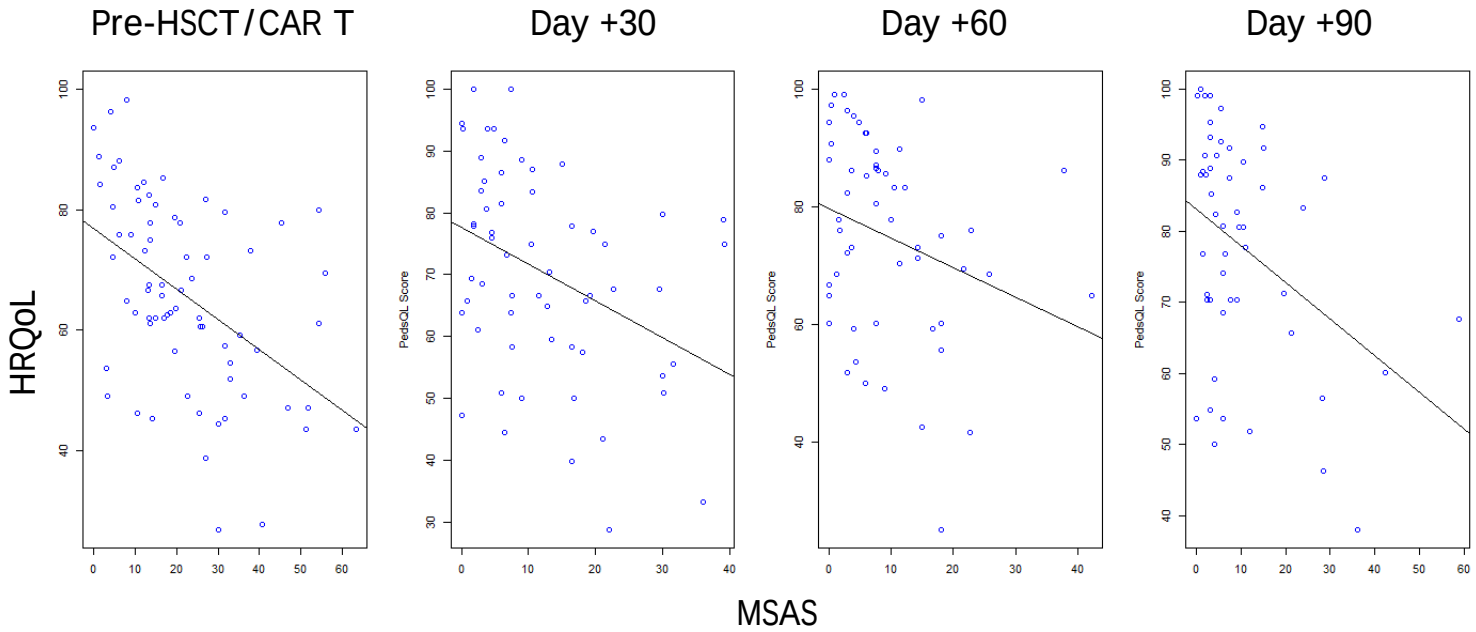
7 – 12 years

Appetite (72%)	Itching (44%)	Pain (27%)	Appetite (30%)
Nausea (61%)	Pain (41%)	Nausea (27%)	Nausea, Sleep (27%)
Pain (44%)	Nausea (34%)	Sleep (18%)	

13 – 18 years

Nausea (76%)	Energy (50%)	Energy (43%)	Energy (36%)
Energy (68%)	Hair Loss, Skin Change (47%)	Pain, Nausea, Skin Change (33%)	Difficulty Concentrating (29%)
Pain (60%)			Nausea (25%)

Child Symptoms and HRQoL



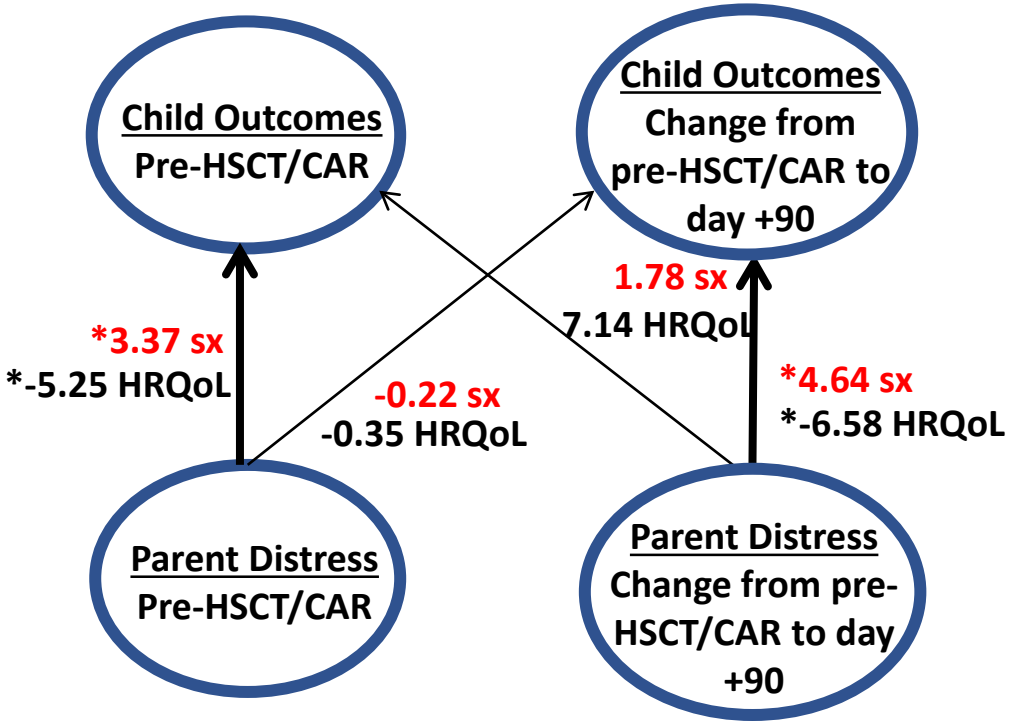
Pre-HSCT/CAR T	Day +30	Day +60	Day +90
r = -0.48	r = -0.38	r = -0.27	r = -0.39
p <0.001	p = 0.003	p = 0.044	p < 0.005

Parent Psychological Distress

	Normative Means (non-clinical samples)	Pre-HSCT /CAR T	Day +30	Day +60	Day +90
			Mean (SD)		
Stress	19.4	35.9 (4.0)	34.9 (4.0)	34.1 (3.8)	34.3 (3.4)
Anxiety	6.6	10.1 (9.5)	8.2 (7.7)	8.4 (9.7)	7.8 (8.7)
Depression	9.14	13.8 (9.0	12.6 (8.2)	11.2 (8.8)	11.1 (9.2)

Relationship Between Parent and Child Outcomes

- A significant relationship was noted between parent distress and child symptoms and HRQoL after adjusting for patient and parent age, gender, diagnosis and therapy type (autologous HSCT, allogeneic HSCT or CAR T cell therapy).
- When parent distress was higher at baseline, child HRQoL was lower.
- As parent distress increases over time, child HRQoL decreases.
- As parent distress increases over time, child symptom burden increases.



* = $p < 0.05$, numbers along the arrows indicate model coefficients

Conclusions

- Children can experience high symptom burden and low HRQoL, particularly prior to cell infusion.
- Procedural anxiety is an HRQoL domain of great concern for children and adolescents throughout HSCT and CAR T-cell therapy.
- Parents experience heightened distress throughout their child's HSCT or CAR T-cell therapy.
- Parent psychological distress is associated with poor child HRQoL and increased symptom burden.

Practice Implications

- Education and individualized interventions to support patients through common procedures (dressing changes, ports, bone marrow aspirates/LPs).
- Routine, comprehensive symptom assessment and multimodal interventions are needed.
- Early palliative care involvement and integration may help to address parent distress and child symptom burden.

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Future Research

- Effect of therapy type, HSCT/CAR-T complications, demographics
  - Risk categorization
- Evaluation of health care utilization
- Symptom domains (Distress, Frequency, Severity)
- Psychoeducational interventions to support parents:
  - Resilience training
  - Problem-solving skills training (Bright IDEAS®)

BrightIDEAS®
Problem-Solving Skills Training

Obtained from https://www.childrensoncologygroup.org/index.php/bright-ideas

Acknowledgements

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