



Using PROMIS to Assess Quality of Life for Children with Brain Tumors

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Background

- ▶ Cancer is one of the leading causes of death and disability in children under 15 years of age. Brain Tumor is the most prevalent solid tumor in children
- ▶ The 5-year survival rate has increased, with > 75% will be alive after 10 years of diagnosis.
- ▶ Although many childhood cancer survivors demonstrate coping and psychosocial adjustment similar to that of their healthy peers, those with academic or other cognitive problems are the major exception, as they experience worse overall adjustment.
- ▶ Studies comparing their QoL to their peers are limited in part due to
 - ▶ unique experiences compared to the majority of pediatric cancer survivors
 - ▶ the functional impact of the tumors and the range of surgical and treatment effects can vary based upon tumor location.
- ▶ PROMIS offers an opportunity to better understand the QOL of pediatric BT patients by comparing how it deviates from that of the US pediatric general population.



Objective

Evaluating QOL reported by BT using PROMIS (Anxiety, Depression, Fatigue, Peer Relationship, Mobility, and Upper Extremity Function) and its potentially influential factors



Methods ~ Subjects

- Recruitment sites
 - Ann & Robert H. Lurie Children's Hospital of Chicago, including Chicago Northwestern Medicine Chicago Proton Center (Formerly, Procure Center, Chicago) and Marianjoy Rehabilitation Hospital
 - Boston Children's Hospital
 - Maryland Proton Treatment Center
- 382 dyads were approached → 330 signed the inform consent → 285 dyads completed the study materials.
 - 248 patients aged 8-21 years,
 - 253 parents of patients aged 8-21 years
 - 63 parents of patients aged 5-7 years.

Methods ~ Subjects

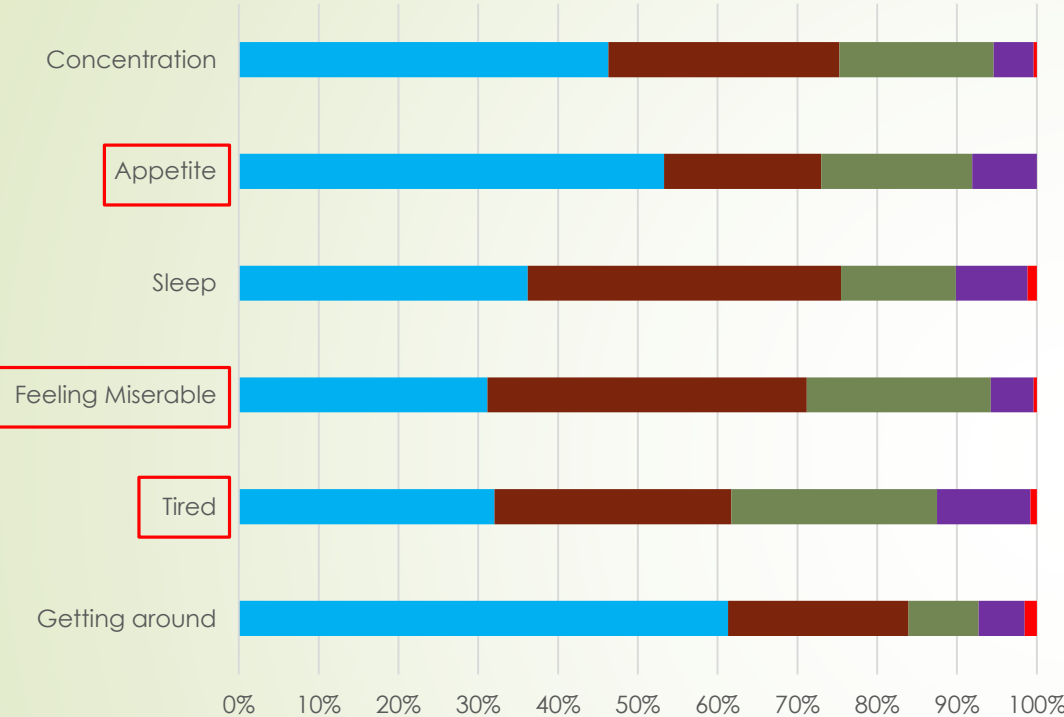
- mean age was 12.3 (SD=4.7); 53.9% were male, 77.1% were White
- 85.5% were newly diagnosed.
- Histology: astrocytic tumors (grades 1-4; 28%), medulloblastoma (21%), and glial tumors ganglioglioma (11.2%);
- Lesion: 22.4% had lesion in posterior fossa, 12.8% in thalamus and 11% in brain stem.
- Treatment: 70.6% received surgery, 71.4% chemotherapy, 57.5% radiation (55.6% proton), and 26.3% had all three modes of therapy. For those who only received one type of treatment, 57.9% had chemotherapy, followed by surgery (32.9%) and radiation (9.2%).
- Averaged years since the diagnosis was 3.5 years (SD=4.1); years since last treatment was 2.1 (SD=3.1).

METHODS ~ Instruments

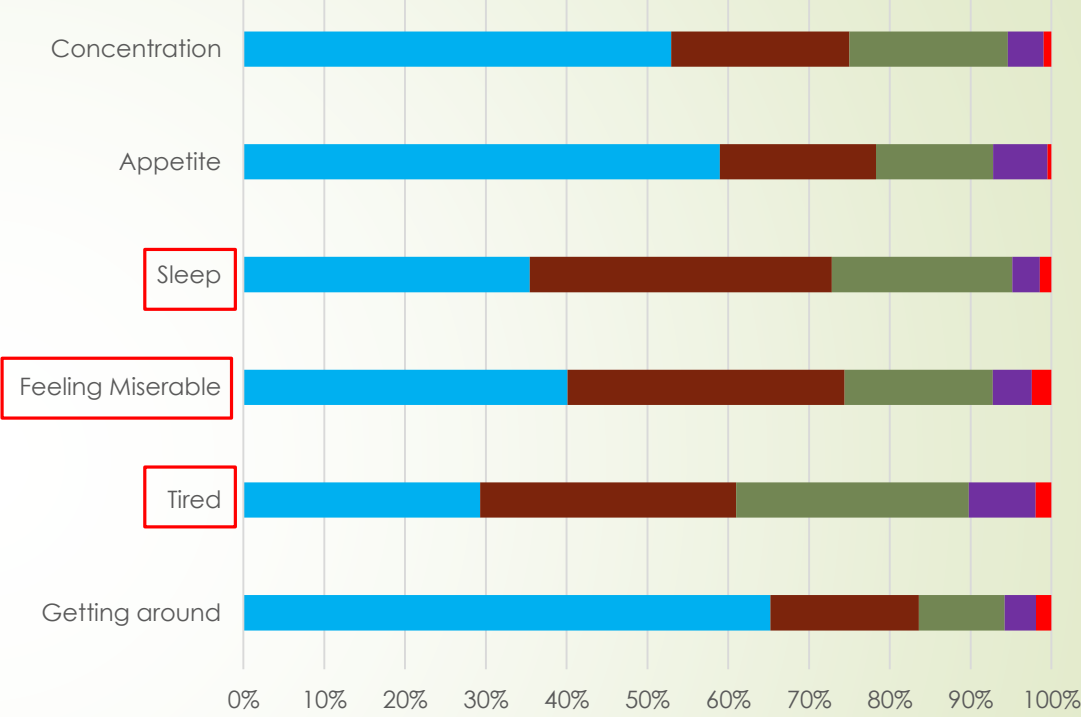
- ▶ Baseline, 3 months, 6 months, 9 months and 1 year.
- ▶ Instruments:
 - ▶ PROMIS pediatric measures of anxiety, depression, fatigue, mobility, upper extremity, and peer relationships (CAT and short-form);
 - ▶ Pediatric Perceived Cognitive Function short-form (PedsPCF)
 - ▶ Symptom Distress Scale (SDS),
 - ▶ the Functional Assessment of Chronic Illness Therapy – Fatigue;
 - ▶ Neuro-Qol (NQ) measures of anxiety, depression, mobility and peer relationships.

Results

Parent-Rated Symptom Distress



Child-rated Symptom Distress



The top three most distressful (scores 3 and higher) symptoms rated by parents were fatigue (38.3%), emotional distress (28.8%), and appetite (27%); while patients rated fatigue (39%), sleep (27.2%) and emotional distress (25.6%) being most stressful.

Results

Item bank	Number of items administered				Time to complete CAT (in min)			
	Mean	SD	Min	Max	Mean	SD	Min	Max
Anxiety	9.7	2.9	5	13	1.38	1.69	<1	13
Fatigue	8.7	2.8	5	13	2.01	3.96	<1	38
Mobility	8.1	3.3	5	13	1.46	0.98	<1	8
Upper Extremity	10.4	2.7	5	13	1.3	0.97	<1	8
Depression	8.3	3.4	5	13	1.31	2.46	<1	28
Peer relationship	8.1	3.2	5	15	1.49	1.95	<1	19

It was doable to include PROMIS in pediatric neuro-oncology clinics

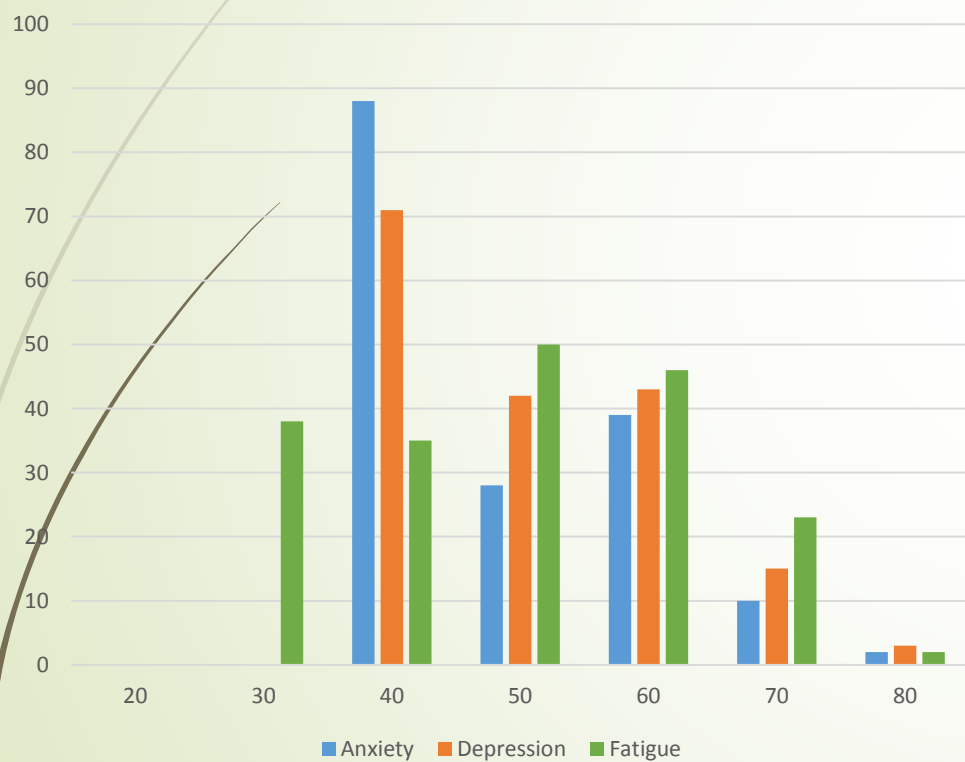
Results



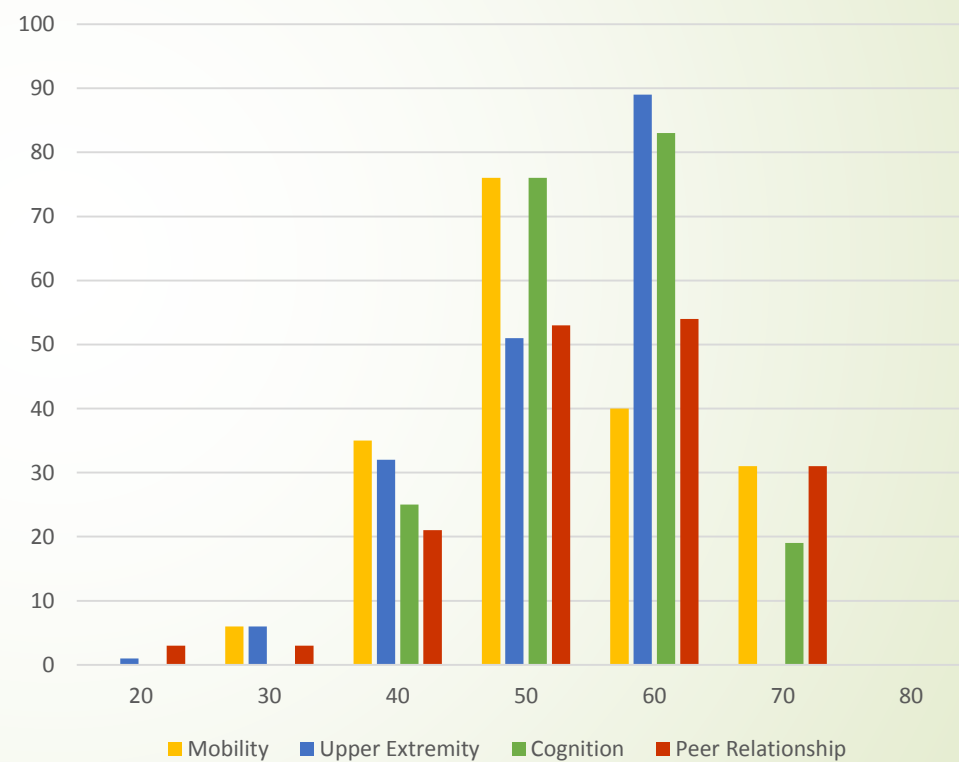
	Mean	SD	Median	Mode	Quantiles									T-Score (in %)	
					100% Max	0.99	0.95	0.9	75% Q3	50% Median	25% Q1	0.1	0.05	>= 50	< 50
Higher scores represents worse symptomatic															
Anxiety	43.1	10.9	39.8	32.4	72.2	72.2	61.6	59.6	51.6	39.8	32.4	32.4	32.4	30.8	69.2
Depression	45.6	11.1	45.9	31.9	72.0	71.8	63.5	60.7	55.0	45.9	35.3	31.9	31.9	35.2	64.8
Fatigue	44.6	13.0	46.1	25.6	73.8	73.6	64.1	61.4	56.1	46.1	32.0	25.6	25.6	36.7	63.3
Higher scores represents better functioning															
Mobility	47.7	9.6	46.2	61.7	61.7	61.7	61.7	61.7	56.4	46.2	41.3	36.3	32.4	37.9	62.1
Upper Extremity	48.4	9.5	50.0	57.2	57.2	57.2	57.2	57.2	57.2	50.0	41.2	34.3	30.7	51.9	48.1
Peer relationship	49.5	10.7	50.3	66.0	66.0	66.0	66.0	66.0	57.5	50.3	41.9	37.7	32.0	51.5	48.5
Cognition	49.5	7.7	50.1	63.9	63.9	63.9	63.9	59.0	54.7	50.1	44.4	38.7	36.6	50.3	49.8

T-Score Distributions across Domains

Higher scores representing more symptomatic



higher scores representing better functioning



vs. Symptom Distress Scale

<u>Child-rated</u>	SDS - Physical		SDS - Fatigue		SDS - Emotion		SDS - Sleep		SDS - Appetite		SDS - Cognition	
	F-value	p	F-value	p	F-value	p	F-value	p	F-value	p	F-value	p
Anxiety	9.91	<.0001	9.93	<.0001	8.78	<.0001	3.69	0.0132	3.98	0.0091	9.71	<.0001
Depression	11.74	<.0001	9.45	<.0001	9.08	<.0001	5.83	0.0008	4.53	0.0044	7.93	<.0001
Fatigue	20.38	<.0001	25.00	<.0001	8.13	<.0001	11.94	<.0001	16.37	<.0001	23.32	<.0001
Mobility	23.89	<.0001	7.33	0.0001	4.53	0.0043	5.15	0.0019	8.05	<.0001	9.28	<.0001
Upper Extremity	10.71	<.0001	5.17	0.0019	1.88	0.1348	0.89	0.4469	5.12	0.0020	3.27	0.0226
Peer Relationships	1.91	0.1295	5.13	0.0021	3.25	0.0235	1.27	0.2864	2.40	0.0694	5.10	0.0022

<u>Parent-rated</u>	SDS - Physical		SDS - Fatigue		SDS - Emotion		SDS - Sleep		SDS - Appetite		SDS - Cognition	
	F-value	p	F-value	p	F-value	p	F-value	p	F-value	p	F-value	p
Anxiety	1.52	0.2121	5.71	0.0010	8.07	<.0001	1.91	0.1303	2.77	0.0441	9.52	<.0001
Depression	3.85	0.0110	10.25	<.0001	14.16	<.0001	3.23	0.0245	10.52	<.0001	11.01	<.0001
Fatigue	8.27	<.0001	16.29	<.0001	11.04	<.0001	4.58	0.0042	13.17	<.0001	12.72	<.0001
Mobility	16.06	<.0001	6.20	0.0005	5.23	0.0018	1.67	0.1757	4.34	0.0057	5.18	0.0019
Upper Extremity	16.18	<.0001	4.84	0.0031	4.25	0.0065	0.63	0.5998	3.04	0.0309	3.50	0.0171
Peer Relationships	1.91	0.1310	2.43	0.0679	4.98	0.0026	5.03	0.0025	1.13	0.3386	2.39	0.0720

QoL vs. Treatment

	Chemotherapy				Radiation				Years since last chemo (<=1 yr vs > 1 yr)				Years since last radiation (<=1 yr vs > 1 yr)				Proton (Y/N) vs. Years since last radiation (<= 1 yr vs. > 1yr)			# of treatment types (0-3) vs Years since last treatment (<= 1yr vs. > 1yr)		
	No	Mean	t Vlaue	p	No	Mean	t Vlaue	p	Source	Mean	t Vlaue	p	Source	Mean	t Vlaue	p	Source	F Value	Pr > F	Source	F Value	Pr > F
Anxiety	No	43.2188	-0.22	ns	No	42.89	-0.47	0.642	<= 1 yr	44.00	1.25	0.2146	<= 1 yr	42.77	-0.71	0.4772	Overall model	1.98	0.1225	Overall model	0.69	0.6291
	Yes	43.6297			Yes	43.71			> 1 yr	41.88			> 1 yr	44.12			Length_Rad	0.24	0.6255	Tx_n	0.78	0.5051
																	Proton (1=yes)	4.28	0.0416	Length_Tx	1.87	0.1737
																	Length_Rad*Proton	1.43	0.2343	Tx_n*Length_Tx	0	1
Depression	No	47.7412	1.33	0.1857	No	44.16	-1.74	0.0831	<= 1 yr	47.09	2.09	0.0384	<= 1 yr	45.44	-0.43	0.667	Overall model	0.3	0.8248	Overall model	0.86	0.5127
	Yes	45.2713			Yes	47.18			> 1 yr	43.52			> 1 yr	46.26			Length_Rad	0.6	0.4423	Tx_n	0.49	0.6894
																	Proton	0.36	0.5508	Length_Tx	0.45	0.5014
																	Length_Rad*Proton	0	1	Tx_n*Length_Tx	2.35	0.1272
Fatigue	No	44.8509	0.05	0.9566	No	42.70	-1.95	0.053	<= 1 yr	45.91	1.59	0.1133	<= 1 yr	44.75	0.09	0.9272	Overall model	1.05	0.3762	Overall model	2.91	0.0148
	Yes	44.7346			Yes	46.45			> 1 yr	42.87			> 1 yr	44.56			Length_Rad	2.73	0.1014	Tx_n	3.24	0.0234
																	Proton	0.12	0.7297	Length_Tx	1.19	0.2776
																	Length_Rad*Proton	0.28	0.5973	Tx_n*Length_Tx	3.66	0.0573
Mobility	No	48.5385	0.76	0.4468	No	49.93	2.81	0.0054	<= 1 yr	46.51	-2.02	0.452	<= 1 yr	48.04	0.85	0.3941	Overall model	0.39	0.7605	Overall model	2.74	0.0208
	Yes	47.3234			Yes	45.91			> 1 yr	49.35			> 1 yr	46.70			Length_Rad	0.83	0.3657	Tx_n	3.53	0.0162
																	Proton	0	0.9722	Length_Tx	0.12	0.7262
																	Length_Rad*Proton	0.34	0.5599	Tx_n*Length_Tx	2.98	0.086
Upper Extremity	No	49.149	0.99	0.3249	No	49.34	1.36	0.1756	<= 1 yr	47.01	-2.28	0.0237	<= 1 yr	47.76	-1.28	0.202	Overall model	4.42	0.0059	Overall model	2.62	0.026
	Yes	47.5692			Yes	47.33			> 1 yr	50.32			> 1 yr	49.82			Length_Rad	8.43	0.0046	Tx_n	2.47	0.0636
																	Proton	2.86	0.0943	Length_Tx	0.51	0.4761
																	Length_Rad*Proton	1.98	0.1626	Tx_n*Length_Tx	5.19	0.024
Peer Relationships	No	49.5362	0.47	0.6373	No	51.22	2.21	0.0282	<= 1 yr	50.97	1.99	0.048	<= 1 yr	50.46	1.76	0.0809	Overall model	1.69	0.1756	Overall model	2.05	0.0745
	Yes	48.6655			Yes	47.48			> 1 yr	41.62			> 1 yr	47.17			Length_Rad	0.27	0.6066	Tx_n	2.69	0.0484
																	Proton	1.53	0.2198	Length_Tx	2.08	0.1517
																	Length_Rad*Proton	3.27	0.0741	Tx_n*Length_Tx	0.12	0.7335

	Mean	SD	Median	Mode	Quantiles									T-Score (in %)	
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Cognition	49.5	7.7	50.1	63.9	63.9	63.9	63.9	59.0	54.7	50.1	44.4	38.7	36.6	50.3	49.8

QoL (≥ 50 vs. < 50) vs. Treatment

	Chemotherapy		Radiation		Years since last treatment				Years since diagnosis				Years since last surgery				Years since last radiation				Years since last chemotherapy				Proton (yes/no)		# of treatment types	
	X ²	p	X ²	p	Source	M	t	p	Source	M	t	p	Source	M	t	p	Source	M	t	p	Source	M	t	p	X ²	p	X ²	p
Anxiety	4.46	0.03	0.21	0.65	>= 50	2.20	-2.67	0.01	>= 50	3.36	-2.72	0.01	>= 50	2.12	-2.24	0.03	>= 50	1.00	-1.23	0.22	>= 50	1.47	-2.31	0.02	7.00	0.01	2.21	0.53
					<50	3.87			<50	5.33			<50	3.54			<50	1.56			<50	2.89						
Depression	4.61	0.03	0.60	0.44	>= 50	2.70	-1.61	0.11	>= 50	3.71	-2.33	0.02	>= 50	2.89	-0.47	0.64	>= 50	1.21	-0.81	0.42	>= 50	1.67	-2.09	0.04	0.45	0.50	1.47	0.69
					<50	3.68			<50	5.32			<50	3.17			<50	1.56			<50	2.80						
Fatigue	1.22	0.27	0.18	0.67	>= 50	2.63	-2.06	0.04	>= 50	4.19	-1.14	0.25	>= 50	2.75	-0.69	0.49	>= 50	1.33	-0.69	0.49	>= 50	1.85	-1.81	0.07	0.26	0.61	4.12	0.25
					<50	3.79			<50	4.94			<50	3.15			<50	1.62			<50	2.77						
Mobility	3.14	0.08	5.45	0.02	>= 50	4.11	1.89	0.06	>= 50	5.25	1.24	0.22	>= 50	3.08	0.06	0.95	>= 50	1.50	-0.12	0.91	>= 50	3.07	1.67	0.10	5.74	0.33	9.03	0.03
					<50	3.02			<50	4.43			<50	3.04			<50	1.55			<50	2.15						
Upper Extremity	4.72	0.03	2.96	0.09	>= 50	4.18	3.15	0.00	>= 50	5.45	2.42	0.02	>= 50	3.21	0.65	0.52	>= 50	1.76	1.71	0.09	>= 50	2.79	1.61	0.11	2.19	0.14	8.31	0.04
					<50	2.44			<50	3.87			<50	2.84			<50	1.07			<50	1.91						
Peer Relationships	1.23	0.27	3.99	0.05	>= 50	4.08	2.07	0.04	>= 50	4.68	-0.34	0.74	>= 50	3.26	0.31	0.76	>= 50	1.50	0.30	0.77	>= 50	2.51	0.12	0.91	1.54	0.21	9.06	0.03
					<50	2.85			<50	4.91			<50	3.07			<50	1.37			<50	2.44						

Conclusions

- It is feasible to administer PROMIS CAT in pediatric neuro-oncology clinics given the limited time needed
- At the group level, children with brain tumor did not demonstrate worse QOL when compared to their peers. However, wide ranges of scores were noted, in which patients with inferior QOL were averaged out by those with superior scores.
 - Depression significantly differentiated patients – chemotherapy, years since dx and since last chemotherapy
 - Fatigue significantly differentiated patients – years since last chemotherapy
 - Mobility significantly differentiated patients – radiation and # of tx types
 - Upper extremity function significantly differentiated patients – chemotherapy, years since last tx and since dx, and # of tx types
 - Peer relationship significantly differentiated patients – radiation, years since last treatment and # of tx types

Question – to what extent PROMIS is “valid”?

Analysis is still on-going



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