

Patient and Parent Experiences of Cancer Symptoms as Assessed by the Memorial Symptom Assessment Scale for Children

Melody Hellsten, DNP, APRN, PPCNP-BC, CHPPN

Symptoms in Childhood Cancer

- Children and adolescents with cancer experience multiple symptoms over the course of treatment
- Symptoms have been shown to cluster together creating challenges in symptom assessment and management
- Symptom burden has been linked to poorer quality of life



Aim

Explore the symptom experience of patients age 7-18 and their primary caregivers based on the symptoms they endorse on a symptom assessment tool

Target Population

English-speaking children ages 7-12 and 13-18 with cancer receiving chemotherapy and their caregivers

Consented 17 patient/caregiver dyads



Memorial Symptom Assessment Scale

- Scales based on Adult MSAS for two age groups
 - 10-18 (Collins, 2000)
 - 30 symptom related questions
 - Individual symptom and total MSAS score
 - 3 subscale scores – Psych, Phys, Global Distress
 - **Chronbach α for Psych (0.83), Phys (0.87), GDI (0.85)**
 - 7-12 (Collins, 2002)
 - 8 symptom questions
 - Individual symptom and total MSAS score
 - Frequency, Severity, Distress **Overall α 0.67**
- Provides multidimensional assessment of symptoms
- Most widely used scale in pediatric oncology symptom research



Demographics

	Overall (n=17)	MSAS 7-12y (n=10)	MSAS 13-18y (n=7)
Age in years			
Mean	11.6	9	15.3
Sex			
Male/Female No. (%)	12/5 (70.6/29.4)	7/3 (70/30)	5/2 (71.4/28.6)
Diagnosis			
Leukemia No. (%)	11 (64.7)	7 (70)	4 (57.1)
Lymphoma No. (%)	1 (5.9)	0 (0)	1 (14.3)
Osteosarcoma No. (%)	3 (17.6)	2 (20)	1 (14.3)
Ewing's Sarcoma No. (%)	1 (5.9)	0 (0)	1 (14.3)
LCH No. (%)	1 (5.9)	1 (10)	0 (0)

* 2 females (1 adolescent and 1 child) completed the MSAS, but not the interview portion of the study



Mixed Methods Approach

MEMORIAL SYMPTOM ASSESSMENT SCALE (13-18)

- Validated Symptom Assessment Tool

Study Participant Code# _____

INSTRUCTIONS: We have listed 30 symptoms below. Read each one carefully. If you have had the symptom during this past week, circle YES. If YES, let us know how OFTEN you had it, how SEVERE it was usually and how much it BOTHERED OR DISTRESSED you by circling the appropriate answer. If you DID NOT HAVE the symptom, circle NO.

DURING THE PAST WEEK DID YOU HAVE ANY

1. DIFFICULTY CONCENTRATING or PAYING ATTENTION?				
		1. YES or 2. NO		
If YES:				
How often did you have it?				
1 - Almost never	2 - Sometimes	3 - A lot	4 - Almost always	
How severe was it usually?				
1 - Slight	2 - Moderately	3 - Severe	4 - Very severe	
How much did it bother or distress you?				
0 - Not at all	1 - A little bit	2 - Somewhat	3 - Quite a bit	4 - Very much

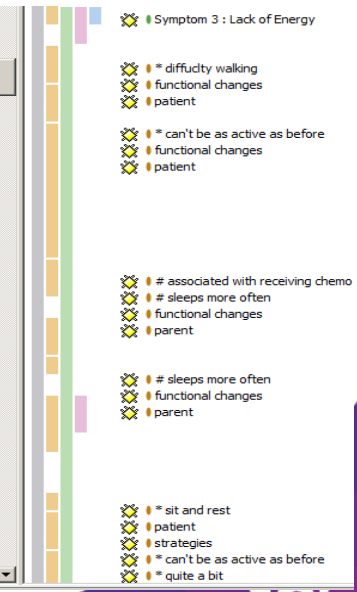
Semi-structured Interview

Data Analysis

MSAS Scores

Themes

I: That is good. The next one you talked about is lack of energy and that you have it a lot and that it is pretty severe? How often would you say you get that?
 P: Hmmmm. When...it just depends what I am doing. So like...I get tired just walking pretty much sometimes. Not through here. I just like, keep walking. I get tired I. Pretty tired I guess.
 I: And is that something that has gone on since you started chemo or is that a more recent thing?
 P: since I started
 I: Ok. I guess you said it was severe. Is that with pretty much any activity?
 P: Uh huh
 I: Does it keep you from doing most of the things you like to do?
 P: Uh huh
 I: And what kinds of things are that? What do you like to do?
 P: Basketball. Jog. Walk.
 I: Normal teenage activities.
 M: he will be awake at some points. When he starts a new. Like he had a pretty heavy chemo last Friday and then he slep pretty much all day Saturday, Sunday and Monday.
 P: yeah. Napping until like 1 or 2 o'clock
 I: So does sleeping help? Or do you just want to sleep?
 P: I just want to sleep
 M: He used to not sleep this much before. He sleeps a lot more now
 P: yeah
 I: Does anything help with the lack of energy? Anything that you do that seems to
 P: Stop and rest
 M: sleeping.
 I: Sleeping. Resting. All of the things your body wants you to do
 M: Yeah sleeping because his body isn't using the energy
 P: I will just sit down I guess.
 I: It is really Any activity that causes it. You said you notice it with most activities?
 P: Yeah
 I: And you said it bothers you quite a bit? What about it bothers you?
 P: That I can't do it



MSAS Scoring

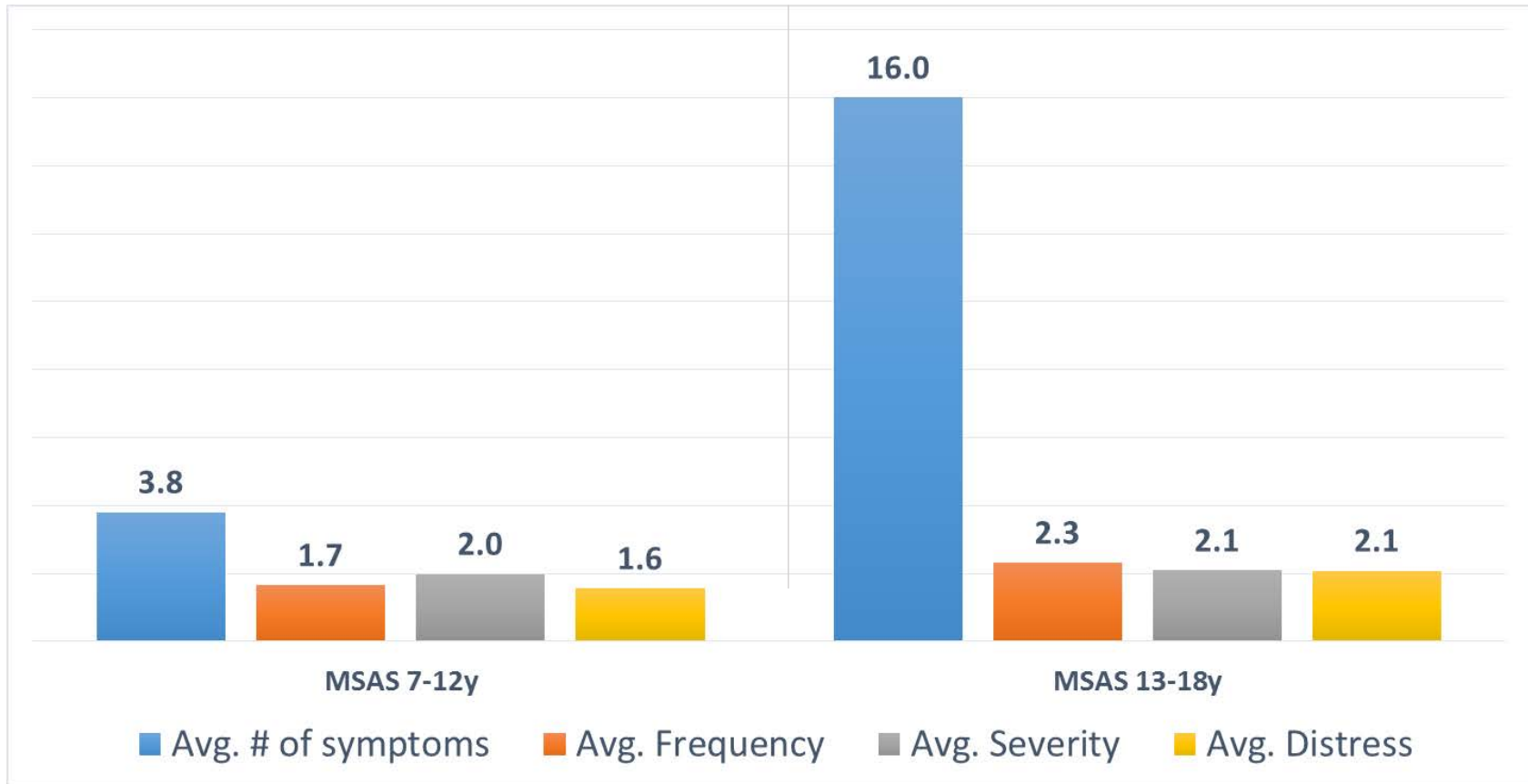
- Symptom Score
 - Equals the average scores for severity, distress, frequency
 - 7-12 likert scale 0-3, max score = 9
 - 13-18 likert scale 0-4, max score = 12
- MSAS Total Score
 - 7-12 – avg of all 8 symptom scores
 - 13-18 – avg of all 30 symptom scores
- Subscale Scores – 13-18 only
 - Psych – avg of 6 psychological symptom scores
 - Phys – avg of 11 physical symptoms
 - Global Distress Index – avg of 10 highly prevalent symptoms



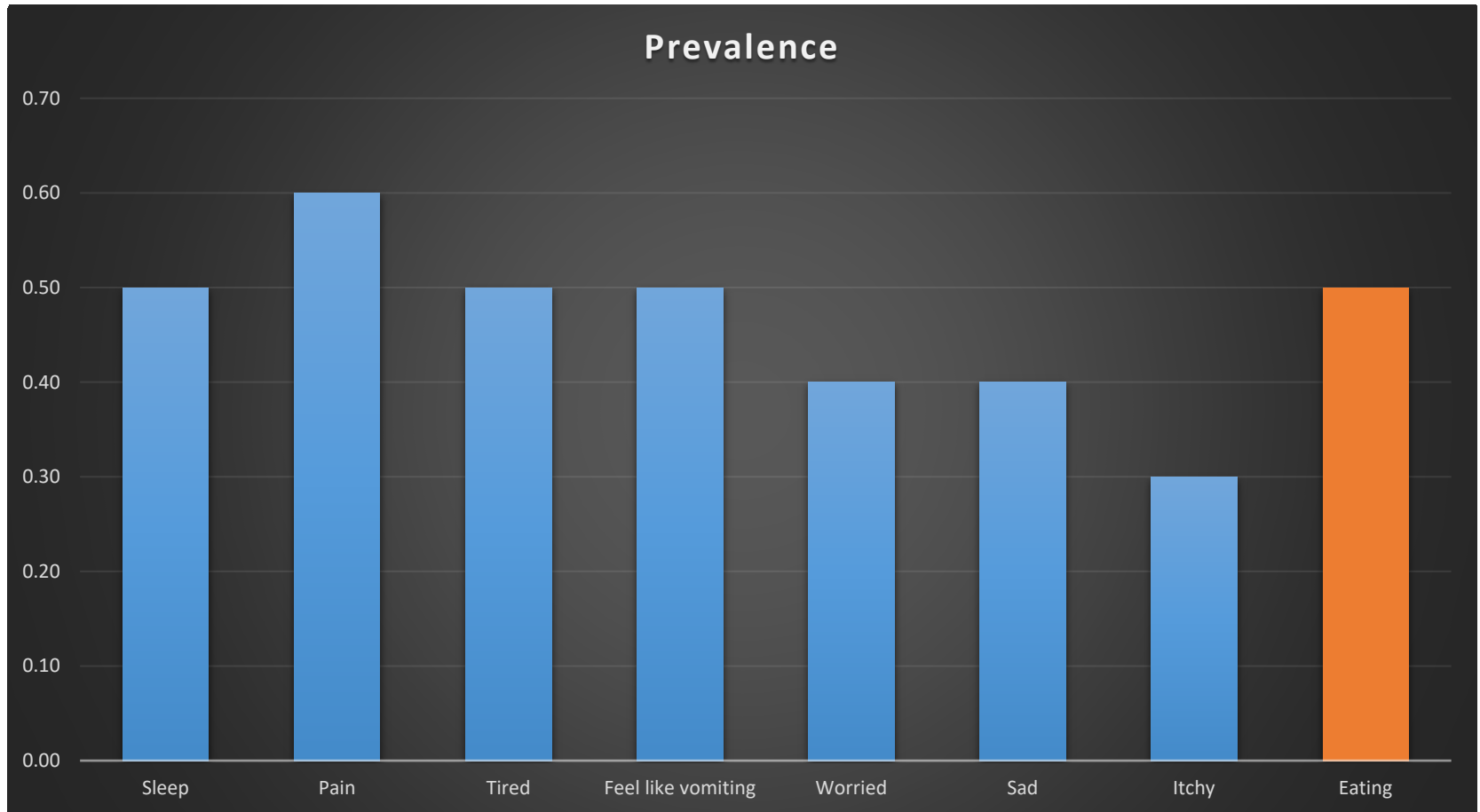
Results

Age 7-12, 8 symptom questions

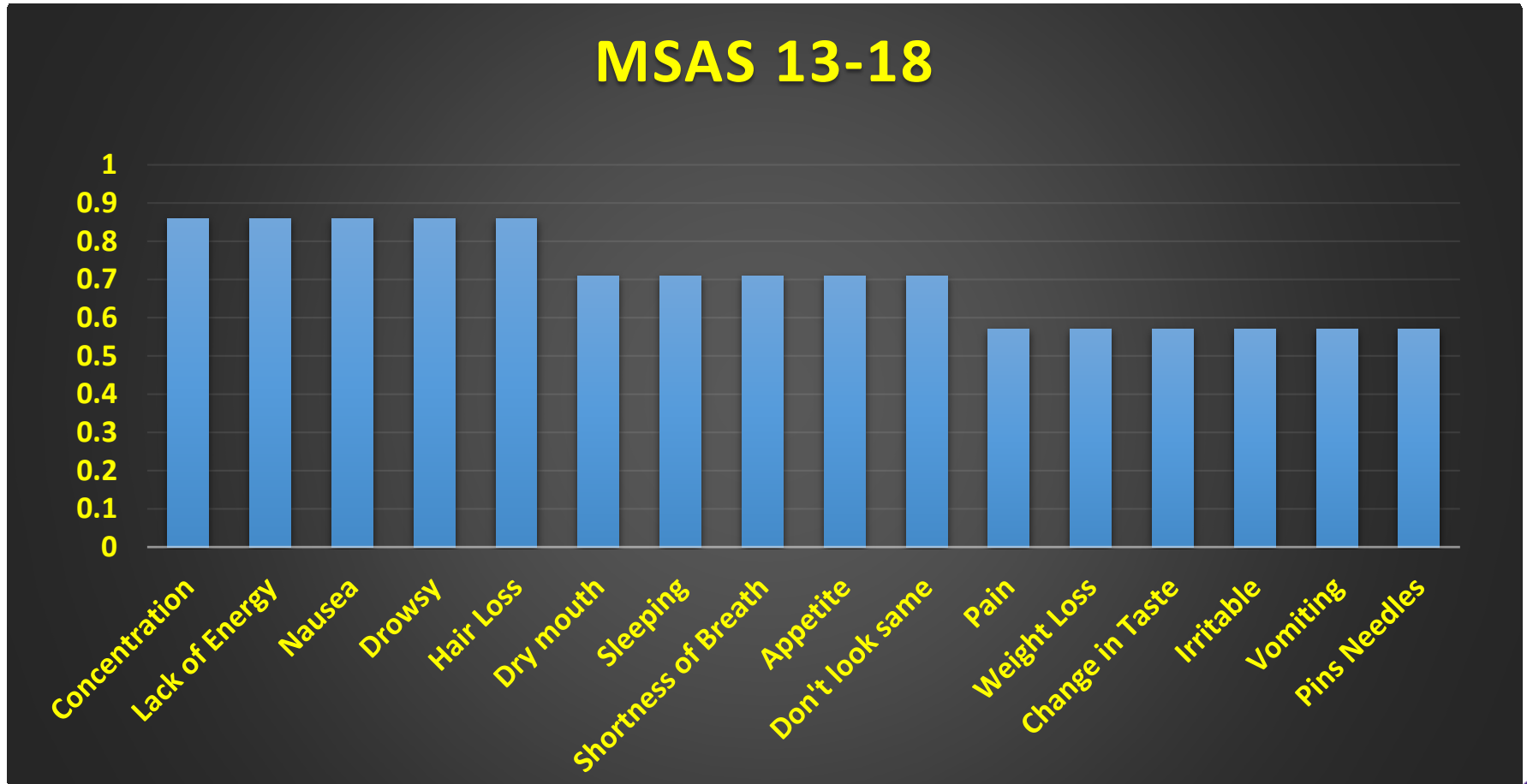
Age 13-18, 30 symptom questions



Symptom Prevalence

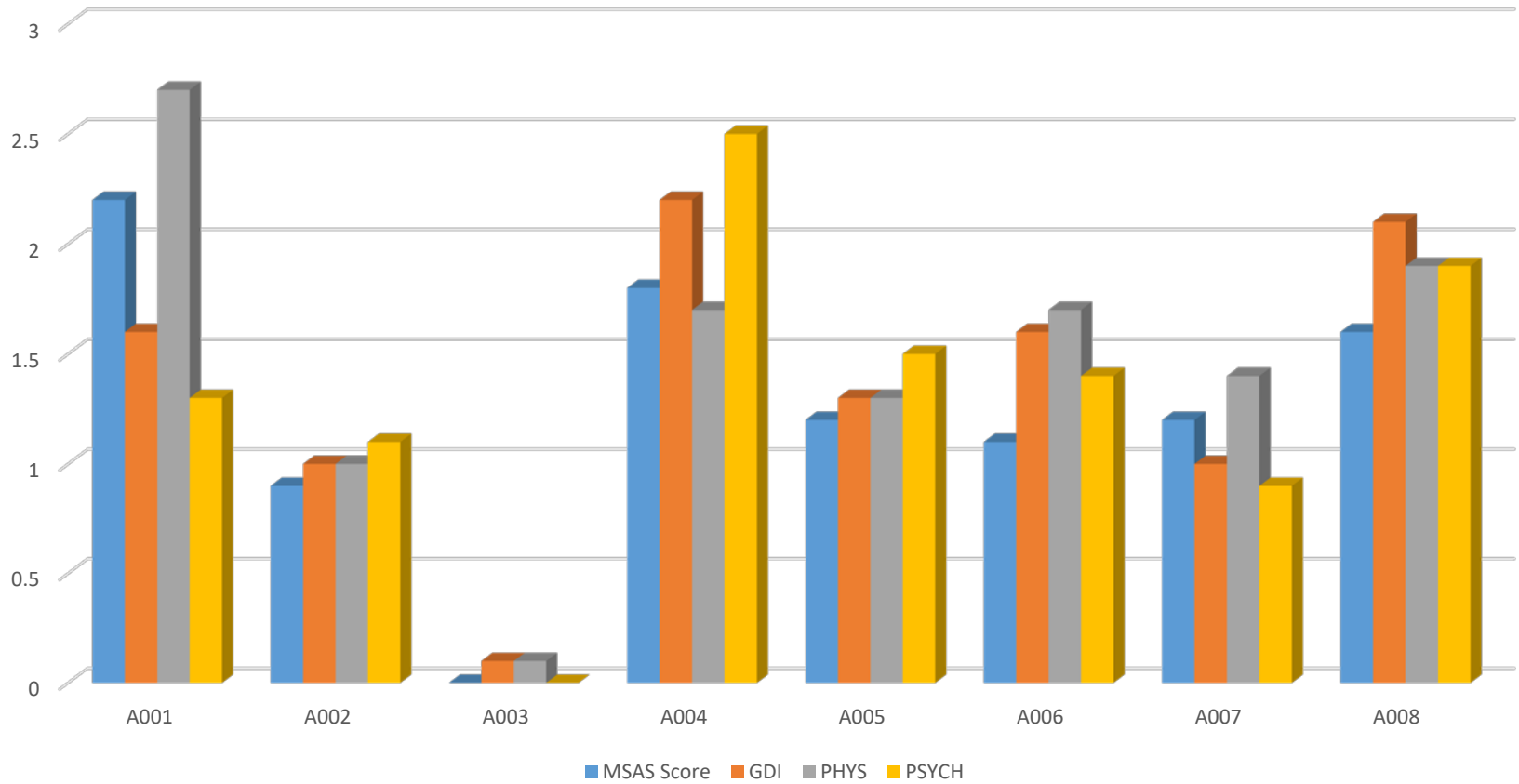


Symptom Prevalence



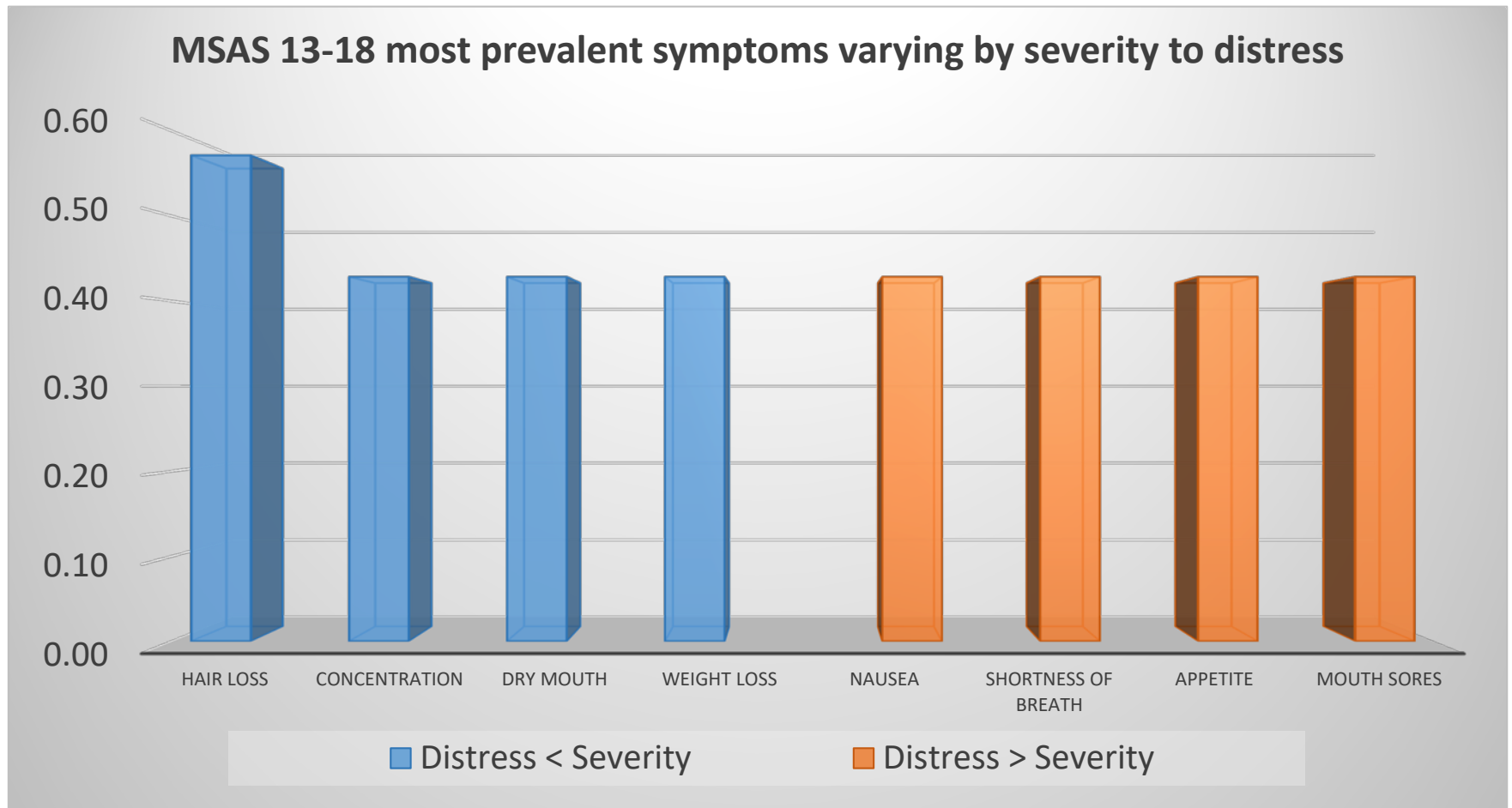
MSAS 13-18 Subscales

MSAS 13-18



Severity vs Distress

Persistent discussion in literature about relationship of severity to distress



Severity vs Distress

3. Lack of Energy	Frequency	Description	Severity	Description	Distress	Discription	
		4	Pretty Constant	3	"summer was spent rollerbladding, playing soccer	2	"it's annoying being tired , which I consider distressing
		1	almost everytime I do somethihng like walk up stairs	2	pretty sluggish today	1	Yeah because when my friends come over I am a litle tired and I can't really do much. And I would like it to be easier to get around but it is kind of hard to do with a lack of energy
		3		2	if I were to try doing something I get really tired. I guess just I lack energy during that time but I get tired really fast doing whatever. I run out of breath.	3	yeah pretty much. Even like when I play guitar, my fingers don't feel the same. They seem to get so tired. I feel like I can't do much really.
		3	just depends what I am doing. So like....I get tired just walking pretty much sometimes. Not through here. I just like, keep walking. I get tired I. Pretty tired I guess.	3	I: pretty much any activity? P: Uh huh	3	I: Does it keep you from doing most of the things you like to do? P: Uh huh
		2	when I get off the chemo, it really knocks me out.	3	Feel so tired, so worn out. Sometimes I feel like my body dying, like my cells dying...	1	It doesn't bother me as much as I thought it would



Patient-Parent Experience

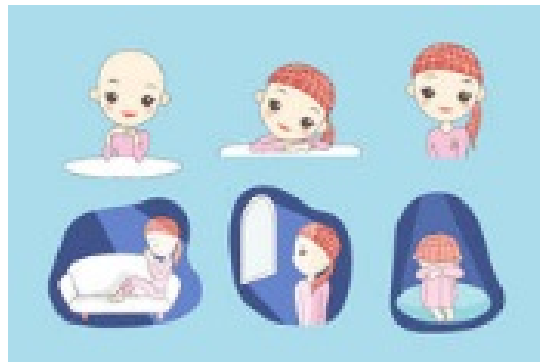
Concentration	Frequency	Description	Severity	Description	Distress	Description
		3 P: 'throughout treatment'; M: 'most of the time'	2		1 P: 'cant focus, read books' M: 'times can't do anything, just lays there'	
		1 P: "guess I would change it to a little bit more, I'm worried I might get held back"	3 P: 'Just sit and stare'		2 P: "how long it takes me to do my work - won't get it done on time"	
		3 P: "usually after chemo...by the weekend it goes away"	3 P: "I don't know it was really hard to focus on everything....just like being at home I couldn't focus watching TV or anything"		3 P: "it made me slack off sometimes...in school"	
		2 P: every day	2 P: "I totally forgot what you even asked'..' I can't - not a big deal"		1	
		2 when doing homework, things that need attention	2 Not that bad, sometimes I just need to focus. Can't focus, a lot is going on in my head		4 I'm not a normal kid anymore. Stresses me out, ...I get frustrated with myself.	



Expectation



k22515197 www.fotosearch.com



Expectations

“[I expected] to feel like I was sick all of the time.”



Function

**"Even when I play guitar
my fingers don't feel the
same. They get so tired. I
feel like I can't do much
really."**



Peer Relationships

"Yeah because when my friends come over I am a little tired and I can't really do much and I would like for it to be easier to get around but it is kind of hard with a lack of energy."



Emotions

“I want to go out because I feel ok, but my body isn’t ok. I don’t quite understand that. It is frustrating and I get mad. I am used to being outside all of the time.”



Family Life

"I think the distressing part is I don't want to be irritable...Normally I am not irritable. They run around the house screaming and I just ignore them. Now, I am like, 'Get them out!'"

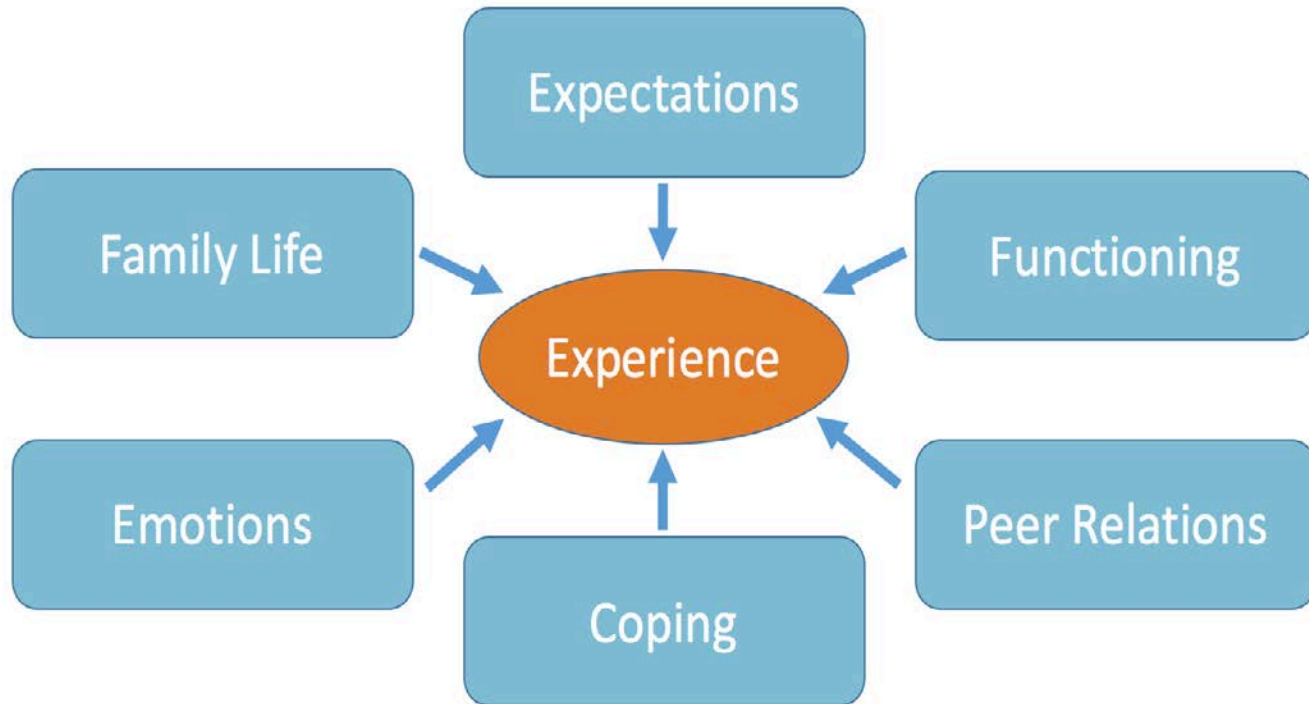


Coping

**"I say it is just
something you got to
get through if you want
to live."**



An Emerging Story...



Conclusions

- Experiential symptom assessment enhances a numerically-based tool
 - Symptoms thought of across disease trajectory vs episodic in nature
 - Symptoms cluster together, are not always independent of one another
- Understanding symptom experience may facilitate improved management, anticipatory guidance and coping
- More work is needed to understand clinical relevance of MSAS scores in directing and evaluating symptom management interventions



Research Team

- Melody Hellsten, DNP, RN, PPCNP-BC
 - Texas Children's Hospital/ Baylor College of Medicine
- Hayden Leeds, MS 3
 - Oregon Health Science Center
- Stacey Berg, MD
 - Texas Children's Hospital/ Baylor College of Medicine
- Patty Baxter, MD
 - Texas Children's Hospital/ Baylor College of Medicine
- Julie Brackett, MD
 - Texas Children's Hospital/ Baylor College of Medicine
- Geri Wood, PhD, RN
 - University of Texas Health Science Center at Houston School of Nursing

