# Understanding Skull Base Symptom Burden from the Patient's Perspective – **Developing a Symptom Burden Measurement for Patients with Complex** Malignant and Benign Skull Base Tumors THE UNIVERSITY OF TEXAS **MD**Anderson

Making Cancer History<sup>®</sup>

**Cancer** Center

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	Experts		n		Symptom	Dis	sease	Trea	tment	Disease 8	k Treatmen	t Expert pane			
Patients			12		Fatiguo	N 1	% 12.0	N 19	% 62.1	N 10	% 65.5	mean score			
Caregivers	5		12	-	Problems with hearing	3	10.3	10	41.4	13	44.8	3.15			
Physicians	:	_	_	-	Pain	15	51.7	18	62.1	22	75.9	3.13			
I	Endocrinology				Ear blockage or drainage	1	3.4	4	13.8	4	13.8	3.04			
Μ	edical Oncology				Nasal stuffy, drainage or crusting	7	24.1	12	41.4	16	55.2	3			
	Neurosurgerv		12		Disturbed sleep	4	13.8 3.4	12	41.4 24.1	14 8	48.3	2.96			
ſ	Ophthalmology				Difficulty chewing and swallowing	3	10.3	9	31	11	37.9	2.94			
Otolaryngology				Problems with vision	9	31	13	44.8	18	62.1	2.91				
Padiation Oncology			Distress	5	17.2	11	37.9	13	44.8	2.91					
Hoolth pro	widers:			_	Ringing in ear	2	6.9	6	20.7	7	24.1	2.89			
Health providers:				Dizziness/vertigo	1 5	3.4	6	24.1	8	24.1	2.87				
	Audiology			·	Difficulty eating	1	3.4	6	20.7	6	20.7	2.83			
N	europsychology				Dry Mouth	0	0	5	17.2	5	17.2	2.83			
	Nursing		11		Problems with balance	7	24.1	7	24.1	10	34.5	2.81			
	Nutrition				Coughing and chocking with food	1	3.4	3	10.3	4	13.8	2.81			
Oral Surgery			Difficulty with voice and speech	4	13.8	11	37.9	13	24.8	2.79					
Physical Therapy			Mucus in mouth and throat	0	0	2	6.9	2	6.9	2.72					
Speech and Language Pathology				Sadness	2	6.9	9	31	9	31	2.7				
				-	Memory changes	1	3.4	8	27.6	9	31	2.7			
Table 2: (	Cohort characte	rist	ics		Difficulty speaking (finding words)	1	3.4	3	10.3	4	13.8	2.7			
Cha	aracteristics	n	%	-	Change in appearance	8	27.6	14	44.8	15 7	51.7	2.66			
Sex	Male	17	59	-	Nausea	4	13.8	/ 10	34.5	13	44.8	2.62			
	White	18	62	-	Dry eye	0	0	4	13.8	4	13.8	2.6			
	Black	3	10		Dry nose	0	0	2	6.9	2	6.9	2.6			
Race	Hispanic	1	3		Limited mouth opening	0	0	2	6.9	5	17.2	2.55			
	Other	7	24		Nose bleeds	3	10.3	2	6.9	4	13.8	2.53			
Disease	Disease free	18	62	-	Numbress or tingling	0 3	10.3	2	0.9 34 5	3 12	10.3 41.4	2.47			
Status	With disease	11	38		Face droop	3	10.3	3	10.3	5	17.2	2.43			
-	Malignant	15	52	-	Dry Throat	0	0	1	3.4	1	3.4	2.43			
iumor	Benign	14	48		Stiff/tight neck	0	0	5	17.2	5	17.2	2.4			
C:+(	Anterior	8	28	-	Skin changes	1	3.4	6	20.7	7	24.1	2.32			
SITE OF	Central	7	24		Vomiting Excessive tearing	3	10.3	3 2	10.3	5	1/.2	2.3			
Disease	Lateral	8	28		Muscle spasm	0	0	2 1	3.4	2 1	3.4	2.3			
Origin	Posterior	6	20		Problems with teeth and gums	1	3.4	2	6.9	3	10.3	2.26			
	I-II	10	35	-	Loss of coordination	1	3.4	0	0	1	3.4	2.26			
Stage	III-IV	16	55		Loss of appetite	0	0	9	31	9	31	2.19			
	N/A	3	10	_	Feeling cold	0	0	1	3.4	1	3.4	2.13			
	Active treatment	9	31	_	Bite is off	0	0	0 3	20.7	2	20.7	2.11			
	Surgery	24	82		Loss of tears	0	0	1	3.4	1	3.4	2.09			
	Endo	15	35		Tongue/throat spasm	1	3.4	0	0	1	3.4	2.09			
Treatment	Open	14	30		Excess/frequent urination	0	0	3	10.3	3	10.3	2.06			
	Both	5	17		Constipation	1	3.4	0	0	1	3.4	2.04			
	Radiotherapy	17	59	-	Eye twitch	0	0	1	3.4	1	3.4	1.89			
	Systemic Therapy	10	35	_	Joint swelling	1	3.4	1	3.4	2	5.4 6.9	1.83			
Number of	0	2	7		Hand/feet swelling	1	3.4	0	0	1	3.4	1.81			
Гreatment	1	9	31		Diarrhea	0	0	1	3.4	1	3.4	1.79			
Modalities	2	12	41		Breast changes	2	6.9	0	0	2	6.9	1.55			
Received	3	6	21		Red eye	0	0	2	6.9	2	6.9	1.01			
Number of Treatment Modalities Received		2 9 12 6	7 31 41 21		Hand/feet swelling Diarrhea Breast changes Red eye	1 0 2 0	3.4 0 6.9 0	0 1 0 2	0 3.4 0 6.9		3.4 3.4 6.9 6.9				
MDAS	SI Core Items	-		( Ja					Sk	ull Base	Specific	Items			
Pain				Л. П.						עודוכעוty swallowing/chewing					
	Fatigue	Ta	able	e 4: Pre	IIminary WDASI-Skull	Ва	ase		Diffi	culty wi	th voice/	speech			
	Nausea									Chan	ge in tast	e			
Disti	urbed sleen									Smel	II changes	S			
	arnea siecp										1 · ·				

	Experts		n	_	Symptom	Disease		Treatment		Disease & Treatmen		t Expert panel	
Patients			12	) -	Fatigue	N 	% 13.8	N 18	% 62.1	N 19	65.5	mean score	
Caregivers	5		12		Problems with hearing	3	10.3	10	41.4	13	44.8	3.15	
Physicians				_	Pain	15	51.7	18	62.1	22	75.9	3.13	
,	Endocrinology				Ear blockage or drainage	1	3.4	4	13.8	4	13.8	3.04	
Γ./	edical Oncology				Nasal stuffy, drainage or crusting	7	24.1	12	41.4	16	55.2	3	
IVI			10		Change in taste	4	13.8	12	41.4	14	48.3	2.96	
	Neurosurgery		12		Disturbed sleep	1	3.4	7	24.1	8	27.6	2.96	
Ophthalmology					Difficulty chewing and swallowing	3	10.3	9	31	11	37.9	2.94	
Otolaryngology					Distress	5	31 17.2	11	44.0 37.9	10	02.1	2.91	
Radiation Oncology					Ringing in ear	2	6.9	6	20.7	7	24.1	2.89	
Health pro	oviders:				Drowsy	1	3.4	7	24.1	7	24.1	2.87	
	Audiology				Dizziness/vertigo	5	17.2	6	20.7	8	27.6	2.85	
N	euronsychology				Difficulty eating	1	3.4	6	20.7	6	20.7	2.83	
IN	Nursing				Dry Mouth	0	0	5	17.2	5	17.2	2.83	
	Nursing		11		Problems with balance	7	24.1	7	24.1	10	34.5	2.81	
	Nutrition				Change in small	1	3.4	3	10.3	4	13.8	2.81	
	Oral Surgery				Difficulty with voice and speech	4	13.8	11	37.9 13.8	13	44.8 2/ 1	2.79	
Р	hysical Therapy				Mucus in mouth and throat	0	0	2	6.9	2	6.9	2.72	
Speech a	nd Language Patho	logy	/		Sadness	2	6.9	9	31	9	31	2.7	
		-07		_	Memory changes	1	3.4	8	27.6	9	31	2.7	
Table 7.	Cobort above at a	r;~+;	icc		Difficulty speaking (finding words)	1	3.4	3	10.3	4	13.8	2.7	
Iaple 2: Conort characteri		IIST		-	Change in appearance	8	27.6	14	44.8	15	51.7	2.66	
Cha	aracteristics	n	%	-	Difficulty concentrating	2	6.9	7	24.1	7	24.1	2.64	
Sex	Male	17	59	-	Nausea	4	13.8	10	34.5	13	44.8	2.62	
	White	18	62		Dry eye	0	0	4	13.8	4	13.8	2.6	
Race	Black	3	10		Dry nose	0	0	2	6.9	2	6.9 17.2	2.0	
Nacc	Hispanic	1	3		Nose bleeds	2	10.3	2	6.9		17.2	2.55	
	Other	7	24	_	Mouth and throat sores	0	0	2	6.9	3	10.3	2.55	
Disease	Disease free	18	62		Numbness or tingling	3	10.3	10	34.5	12	41.4	2.43	
Status	With disease	11	38		Face droop	3	10.3	3	10.3	5	17.2	2.43	
Tumor	Malignant	15	52	-	Dry Throat	0	0	1	3.4	1	3.4	2.43	
	Benign	14	48		Stiff/tight neck	0	0	5	17.2	5	17.2	2.4	
	Anterior	8	28	-	Skin changes	1	3.4	6	20.7	7	24.1	2.32	
Site of	Central	7	24		Vomiting	3	10.3	3	10.3	5	17.2	2.3	
Disease	Lateral	8	28		Excessive tearing	1	3.4	2	6.9	3	10.3	2.3	
Origin	Posterior	6	20		Problems with tooth and gums	1	21	1	3.4 6.0	2	3.4	2.3	
Stage	-	10	35	-	Loss of coordination	1	3.4	0	0.5	1	3.4	2.20	
		16	55		Loss of appetite	0	0	9	31	9	31	2.19	
	N/A	3	10		Feeling cold	0	0	1	3.4	1	3.4	2.13	
Treatment	Active treatment	<u>م</u>	21	-	Sweating and hot flush	0	0	6	20.7	6	20.7	2.11	
	Surgory	2/	27	-	Bite is off	0	0	3	10.3	3	10.3	2.09	
	Suigery	24 15	02 25		Loss of tears	0	0	1	3.4	1	3.4	2.09	
	Endo	10	30		Tongue/throat spasm	1	3.4	0	0	1	3.4	2.09	
	Open	14	30		Excess/frequent urination	1	21	3	10.3	3	2.4	2.06	
	Both	5	1/	-	Eve twitch	0	0	1	34	1	3.4	2.04	
	Radiotherapy	1/	59	-	Shoulder droop	1	3.4	0	0	1	3.4	1.83	
	Systemic Therapy	10	35	-	Joint swelling	1	3.4	1	3.4	2	6.9	1.81	
Number of	0	2	7		Hand/feet swelling	1	3.4	0	0	1	3.4	1.81	
Treatment	1	9	31		Diarrhea	0	0	1	3.4	1	3.4	1.79	
Modalities	2	12	41		Breast changes	2	6.9	0	0	2	6.9	1.55	
Received	3	6	21	_	Red eye	0	0	2	6.9	2	6.9	1.01	
MDA	MDASI Core Items   Pain   Fatigue   Table 4: Preliminary MDASI-Skull Base							Skull Base Specific Items Difficulty swallowing/chewing <sup>2</sup> Difficulty with voice/speech <sup>2</sup>					
	Nausea									Chang	ge in taste	2	
Dist	urbed sleep									Smel	I changes		
										Naaa	haing dim		

## Introduction

There are few validated instruments that assess the symptom burden of skull base tumors (SBT) survivors, especially for patients undergoing multimodality treatment for malignant and complex benign tumors. MD Anderson Symptom Inventory (MDASI)<sup>1</sup> was developed to assess symptom burden in cancer patients and validated in 640 patients with both solid and liquid tumors. Our aim is to understand the symptom profile and to explore the utility for developing a skull base (SB) module of MDASI.

## Methods

- In phase I, patients with complex benign and malignant SBT were recruited for individual, semi structured, qualitative interviews. Patients were interviewed with open-ended questions about their experiences at diagnosis, during and after treatment. Recruitment continued until saturation was reached, defined as no new items in 3 consecutive interviews.
- Interviews were recorded, transcribed and reviewed by two investigators to identify symptom items.
- In Phase II, symptoms items generated from Phase I were rated for relevance on a 4-point scale by an expert panel (EP) of patients, caregivers, physicians and health providers. (Table 1)
- Descriptive statistics were used to analyze disease and
- treatment characteristics, and symptom items.
- Symptoms assessed as relevant by the EP and mentioned in the qualitative interviews by >20% of patients were included for consideration for inclusion in the preliminary MDASI-Skull Base for psychometric testing and cognitive debriefing.

#### Results

- Twenty-nine patients were recruited for qualitative interviews, evenly distributed across multiple SB subsites: sinonasal, anterior skull base (e.g. meningioma, sinonasal tumor with significant intracranial extension), central (e.g. craniopharyngioma, pituitary tumor), lateral (e.g. acoustic neuroma, paraganglioma) and posterior skull base (e.g. chondrosarcoma, chordoma). (Table 2)
- Patients were treated with multimodality therapy: 60% had two or more modalities of surgery, systemic therapy and/or radiotherapy. (Table 2)
- Fifty-six items were identified from Phase I and classified as attributable to the disease, the treatment or both (Table 3). Of these, 25 were reported by >20% of patients. Of these, ten were already present in the MDASI core: pain, fatigue, distress, nausea, numbness/tingling, memory changes, loss of appetite, sadness, sleep disturbances, drowsiness. Forty-nine items were rated as > 2.0 by the EP. The 15 additional disease-specific symptoms were identified: problems related to hearing, ear ringing, ear blockage or draining, balance, dizziness,



attention/concentration, vision, smell, taste, chewing/swallowing, voice/speech, stuffy nose/crusting/drainage, nasal dryness, skin problems, changes in appearance.

The final preliminary MDASI-SB comprise of 34 items, including 13 core items, 6 interference items and 15 disease-specific items. (Table 4)

## Contact

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Patients with malignant and complex SBT treated with multimodality therapy experience wideranging symptoms across multiple organ systems. A core group of symptoms are experienced by most patients, regardless of disease subsite. These symptoms form the basis of the preliminary MDASI-Skull Base, which will be validated with Phase III psychometric testing.

## References

- 1. Cleeland CS, Mendoza TR, Wang XS, Chou C, Harle MT, Morrissey M, Engstrom MC. Assessing symptom distress in cancer patients: the M.D. Anderson Symptom Inventory. Cancer. 2000 Oct 1;89(7):1634-46. doi: 10.1002/1097-0142(20001001)89:7<1634::aid-cncr29>3.0.co;2-v. PMID: 11013380.
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