

Supplementary Materials: Assessing Preferences in Patients with Head and Neck Squamous Cell Carcinoma: Phase I and II of Questionnaire Development

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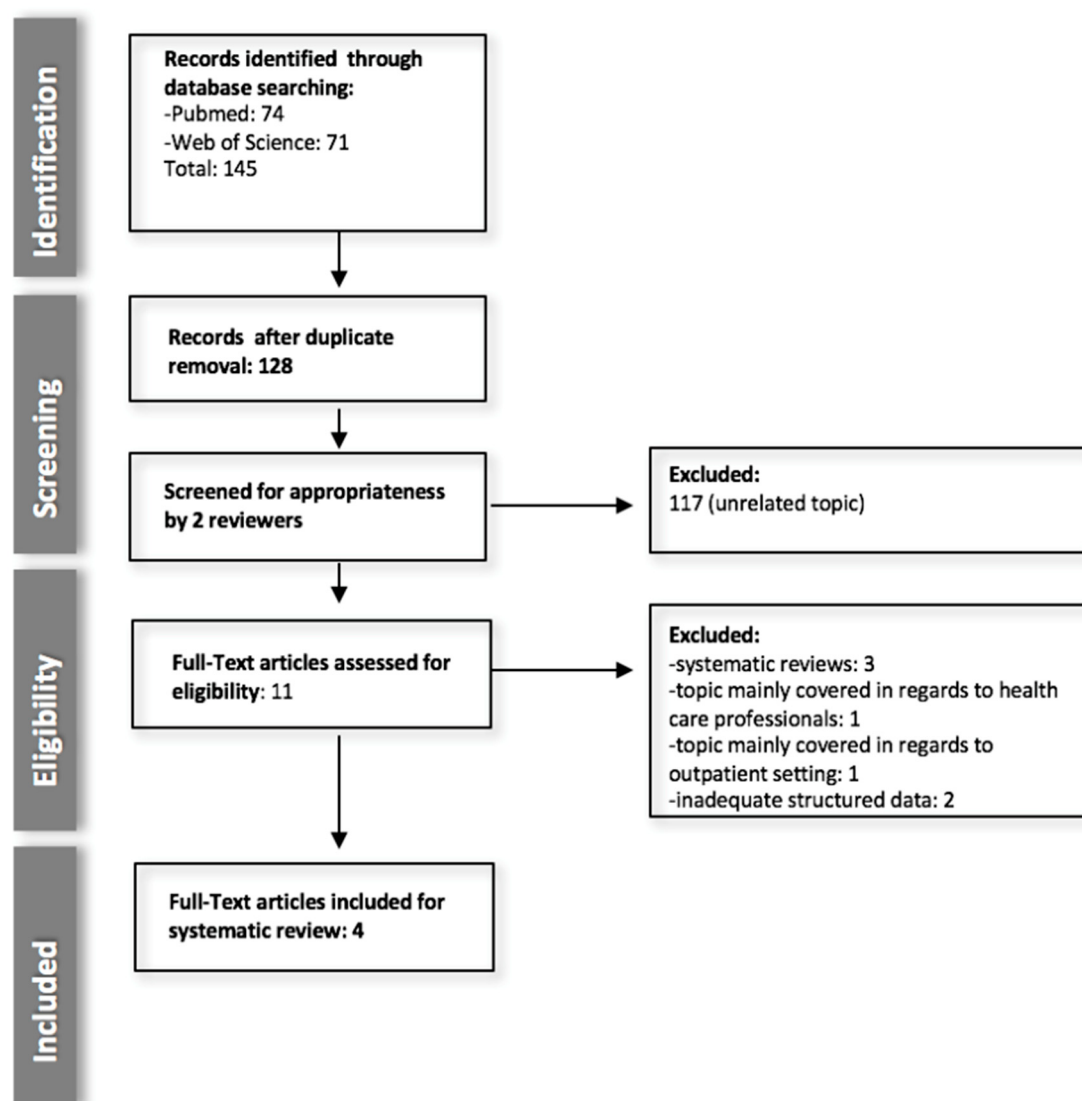


Figure S1. flow chart of literature search.

Table S1. significant associations between selected issues and treating center ($n = 109$; p -value from chi-square or Kendall tau B test).

Issue		Brescia ($n = 32$)	Florence ($n = 10$)	Milan ($n = 22$)	Mainz ($n = 10$)	Sao Paulo ($n = 15$)	Nashville ($n = 20$)	p -value from Chi-square (Kendall tau B)
n	score	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
#1	2	0 (0)	2 (20)	0 (0)	0 (0)	0 (0)	0 (0)	0.008
	3	1 (3.1)	0 (0)	2 (9.5)	0 (0)	1 (6.7)	0 (0)	
	4	31 (96.9)	8 (80)	19 (90.5)	10 (100)	14 (93.3)	20 (100)	
#2	1	0 (0)	1 (10)	0 (0)	0 (0)	0 (0)	0 (0)	0.049
	2	0 (0)	0 (0)	0 (0)	0 (0)	1 (6.7)	0 (0)	
	3	2 (6.3)	0 (0)	5 (23.8)	1 (10)	2 (13.3)	0 (0)	
	4	30 (93.7)	9 (90)	16 (76.2)	9 (90)	12 (80)	20 (100)	
#3	1	1 (3.1)	1 (10)	1 (5.3)	1 (10)	0 (0)	1 (5)	0.018
	2	6 (18.8)	0 (0)	5 (26.3)	0 (0)	1 (6.7)	2 (10)	
	3	5 (15.6)	6 (60)	6 (31.6)	3 (30)	1 (6.7)	11 (55)	
	4	20 (62.5)	3 (30)	7 (36.8)	6 (60)	13 (86.6)	6 (30)	
#21	1	6 (18.8)	1 (10)	2 (10)	0 (0)	0 (0)	3 (15.8)	0.04
	2	6 (18.8)	2 (20)	8 (40)	0 (0)	1 (6.7)	8 (42.1)	
	3	7 (21.9)	3 (30)	5 (25)	4 (40)	9 (60)	6 (31.6)	
	4	13 (40.5)	4 (40)	5 (25)	6 (60)	5 (33.3)	2 (10.5)	
#22	1	7 (21.9)	0 (0)	2 (10.5)	1 (10)	1 (6.7)	1 (5.3)	0.043
	2	3 (9.4)	3 (30)	4 (21.1)	0 (0)	1 (6.7)	7 (36.8)	
	3	7 (21.9)	2 (20)	7 (36.8)	1 (10)	8 (53.3)	6 (31.6)	
	4	15 (46.8)	5 (50)	6 (31.6)	8 (80)	5 (33.3)	5 (26.3)	
#24	1	3 (9.4)	1 (10)	0 (0)	0 (0)	0 (0)	4 (21.1)	0.018 (0.017)
	2	3 (9.4)	2 (20)	5 (26.3)	0 (0)	3 (20)	6 (31.6)	
	3	7 (21.9)	2 (20)	9 (47.4)	2 (20)	4 (26.7)	7 (36.8)	
	4	19 (59.4)	5 (50)	5 (26.3)	8 (80)	8 (53.3)	2 (10.5)	
#25	1	2 (6.3)	0 (0)	0 (0)	1 (10)	0 (0)	0 (0)	0.063 (0.032)
	2	4 (12.5)	0 (0)	4 (20)	0 (0)	1 (6.7)	5 (26.3)	
	3	6 (18.8)	1 (10)	6 (30)	3 (30)	5 (33.3)	10 (52.6)	
	4	20 (62.4)	9 (90)	10 (50)	6 (60)	9 (60)	4 (21.1)	
#26	1	2 (6.5)	0 (0)	2 (10.5)	0 (0)	0 (0)	3 (15.8)	0.021
	2	5 (16.1)	0 (0)	5 (26.3)	0 (0)	1 (6.7)	3 (15.8)	
	3	10 (32.3)	3 (30)	5 (26.3)	0 (0)	9 (60)	8 (42.1)	
	4	14 (45.1)	7 (70)	7 (36.9)	10 (100)	5 (33.3)	5 (26.3)	
#28	1	4 (12.9)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0.025
	2	0 (0)	0 (0)	5 (25)	1 (10)	0 (0)	1 (5.6)	
	3	5 (16.1)	0 (0)	2 (10)	1 (10)	1 (6.7)	3 (16.7)	
	4	22 (71)	10 (100)	13 (65)	8 (80)	14 (93.3)	14 (77.7)	

#1: cure of disease; #2: survival (live as long as possible); #3: no pain; #21: social role; #22: normal dental health; #24: social life; #25: respect of desires and dignity; #26: intimacy; #28: being thoroughly and sincerely informed about treatments' efficacy and survival expectation.

Table S2. descriptive analysis of clustered issues and their distribution by treatment subgroups (*p*-value from Kruskal-Wallis test).

Issues: #6 + #13 + #14	Curative (<i>n</i> = 30)	Follow-Up (<i>n</i> = 38)	Palliative (<i>n</i> = 20)	Cronbach's Alpha
mean	10.7	9	10.3	0.68
SD	2.2	2.0	2.0	
min	3	4	6	
max	12	12	12	
<i>p</i> -value from Kruskal-Wallis test	all: <i>p</i> = 0.0001 follow-up vs palliative: <i>p</i> = 0.01 follow-up vs curative: <i>p</i> = 0.0001 palliative vs curative: <i>p</i> = 0.42			
Issues: #16 + #24 + #26	Curative (<i>n</i> = 30)	Follow-Up (<i>n</i> = 36)	Palliative (<i>n</i> = 20)	Cronbach's Alpha
mean	10.5	8.7	9.5	0.74
SD	1.9	2.6	2.5	
min	6	3	4	
max	12	12	12	
<i>p</i> -value from Kruskal-Wallis test	all: <i>p</i> = 0.009 follow-up vs palliative: <i>p</i> = 0.25 follow-up vs curative: <i>p</i> = 0.002 palliative vs curative: <i>p</i> = 0.13			

#6: ability to swallow; #13: normal breathing through mouth and nose; #14: burning mouth; #16: no depression; #24: social life; #26: intimacy.

Table S3. Distribution of issues analyzed separately as Likert-type data (frequencies, median, mode, range, IQR) and preferences (number, percentage) expressed by health care professionals.

Score	1		2		3		4		5		6		7		8		9		10	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	2.7	1	2.8	2	5.5
2	0	0	0	0	1	2.7	6	16.2	4	10.8	3	8.3	14	38.9	5	13.5	9	25	15	41.7
3	0	0	10	27	11	30.6	26	70.3	20	54	16	44.4	17	47.2	20	54	18	50	16	44.5
4	37	100	27	73	24	66.7	5	13.5	13	35.2	17	47.2	5	13.9	11	29.8	8	22.2	3	8.3
Total	37		37		36		37		37		36		36		37		36		36	
Median	4		4		4		3		3		3		3		3		3		2	
Mode	4		4		4		3		3		4		3		3		3		3	
Range	0		3–4		2–4		2–4		2–4		2–4		2–4		1–4		1–4		1–4	
IQR	0		1		1		0		1		1		1		1		1		1	
preference	33		26		28		9		26		29		10		19		10		3	
(%)	(89.2)		(70.3)		(77.8)		(24.3)		(70.3)		(80.6)		(27.8)		(51.4)		(27.8)		(8.3)	
Answer	11		12		13		14		15		16		17		18		19		20	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
1	5	13.9	2	5.5	0	0	1	2.8	1	2.8	1	2.8	2	5.5	2	5.5	1	2.8	0	0
2	21	58.3	10	27.8	9	25	16	44.4	15	41.7	13	36	4	11.2	6	16.7	11	30.5	13	36.1
3	9	25	19	52.8	17	47.2	14	38.9	14	38.8	18	50	14	38.9	15	41.7	15	41.7	18	50
4	1	2.8	5	13.9	10	27.8	5	13.9	6	16.7	4	11.2	16	44.4	13	36.1	9	25	5	13.9
Total	36		36		36		36		36		36		36		36		36		36	
Median	2		3		3		3		3		3		3		3		3		3	
Mode	2		3		3		2		2		3		4		3		3		3	
Range	1–4		1–4		2–4		1–4		1–4		1–4		1–4		1–4		1–4		2–4	
IQR	1		1		2		1		1		1		1		1		2		1	
preference	0		7		16		4		6		4		17		11		12		7	
(%)	(0)		(19.4)		(44.4)		(11.1)		(16.7)		(11.1)		(47.2)		(30.6)		(33.3)		(19.4)	
Answer	21		22		23		24		25		26		27		28					
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%				
1	1	2.8	3	8.3	5	13.9	1	2.8	1	2.7	3	8.1	3	8.1	2	5.4				

2	13	36.1	22	61.2	18	50	6	16.7	2	5.4	13	35.2	13	35.2	3	8.1
3	14	38.9	8	22.2	13	36.1	21	58.3	15	40.5	15	40.5	13	35.2	10	27.1
4	8	22.2	3	8.3	0	0	8	22.2	19	51.4	6	16.2	8	21.5	22	59.4
Total	36		36		36		36		37		37		37		37	
Median	3		2		2		3		4		3		3		4	
Mode	3		2		2		3		4		3		2		4	
Range	1–4		1–4		1–3		1–4		1–4		1–4		1–4		1–4	
IQR	1		1		1		0		1		1		1		1	
preference	5		1		2		8		21		4		4		17	
(%)	(13.9)		(2.8)		(5.6)		(22.2)		(56.8)		(10.8)		(10.8)		(45.9)	

IQR: interquartile range.

Table S4. scoring criteria of issues according to the EORTC module development guidelines.

Criteria	Scoring Criteria	Threshold	Score for Inclusion
1	Mean of patients' Likert score	> 2.0	1
2	Mean of relevance to a specific patients' subgroup (curative intent subgroup; palliative intent subgroup; follow-up subgroup)	> 2.5	1
3	>20% of the patients said yes to inclusion	> 20%	1
4	>30% of HCP said yes to inclusion	> 30%	1

HCP: health care professionals.

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