Excellence in Cancer Care: Supporting the person with head and neck lymphoedema

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Introduction

This study aims to examine the supports required to manage distress and quality of life (QoL) in people with Head and Neck Lymphoedema (HNL), to help support direction of future care.

Head and Neck Lymphoedema (HNL):

- Lesser recognised side effect of head and neck cancer treatment
- 75% of patients will be affected by this condition [1]
- Issue as: impacts swallowing, breathing, QoL

Distress:

“Distress is a multifactorial unpleasant experience of a psychological (ie, cognitive, behavioural, emotional), social, spiritual and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.” NCCN, 2017 [2]

Method: mixed method design

Prospective repeated measures to examine distress, QoL and body image

Measures: at baseline of HNL treatment program, week six, and completion of treatment program (week 22)

1. **Distress** Thermometer

2. EORTC- QoL- Head and Neck

Data analysis: Freidman test, with pairwise comparisons and Bonferroni correction for multiple comparisons. Post hoc tests were completed using Wilcoxon Signed Rank test. All analyses were conducted using SPSS version 22

Qualitative approach to explore the patient’s experience of distress with HNL

Measure: Semi-structured interviews

Data analysis: Interview analysis using a thematic six stage process [3]

Results – Demographics (n=10)

Age	Mean 65.1
Gender	9 males, 1 female
Cancer type	8/10 SCC
Surgery + radiotherapy	n = 8
Radiotherapy + chemotherapy	n = 2
Time post HNC treatment to HNL treatment	6.65 months
Time from HNL treatment to interview	12.9 months
Recurrence	
- from referral to completion HNL treatment	0 (0%)
- from completion HNL treatment to interview	1 (10%)

Results- Phase 2 [4]

Theme One: Psychosocial Impact

Categories	Sub-categories	n	ref	Example
Emotional	I felt....(emotional impact)	10	neg 34 pos 17 tot 51	It made me feel not wanted, an outcast P2 Um getting rid of that lump, the physical side of things and not having it there, that helped enormously, that enabled me to go out into public without worrying about what people are thinking P7
	It reminds you that you’ve got a problem (meaning of the swelling)	5	11	A couple of my good mates said to me “what’s going on with the throat? You haven’t got this cancer back have you?” P6
	Swelling was just part of the treatment	5	9	Oh I just took it as normal course of the operation and treatment and that it was all part of the cycle P9
	So, that’s my philosophy	7	18	You just have to take stock of yourself and dust yourself off and say “come on get on with it” P8
Appearance changes...		10	neg 36 pos 9 tot 45	It was like a roll on the scar and it made you look like an elephant P8 I couldn’t say exactly what was making it change but the appearance of not having that great lump was one P7
Socialisation		5	9	I didn’t want to go out P2

n=number of participants ref=number of times referenced neg=negative pos=positive tot=total

Theme Three: Experience of receiving treatment

Categories	Sub-categories	n	ref	Example participant quotes
Treatment modality	Getting treatment (lymphoedema therapy)	10	43	It decreased (distress) because I had so much confidence in the lovely people who were treating me. They were always concerned and always did a top job P8
	Education/information	5	18	I don’t want my head in the sand, I want to understand and when I understand things better and I think that was the big thing P4
	Self-management	9	24	That gave me a positive attitude and that if I did what I was told to do religiously it would resolve itself to the best it could P4
	Massage	10	30	Massage was magnificent. Every time I had it I could feel the relief instantly P8
	Compression	10	41	The bandage was the biggest help I feel P7 People when they come over say I have underpants on my head P10
	Exercise	6	20	The exercises do make it easier and they actually made it easier for me to swallow too P7
	Lymph tape	3	6	It’s slower but you are aware of the tape being on there so yeah it does push it away P7
I recommend...		9	22	I would suggest is that they follow the directions P1

Discussion

Distress reduces with the delivery of HNL treatment program- people feel supported by therapist availability even if it is for practical intervention.
There is a discrepancy in standardised assessment and the qualitative information that people shared- based on our findings it is recommended asking the person specific questions regarding their experience.
Participants report massage and compression are helpful with reducing swelling- further research is required to determine these benefits.

Conclusion

This study found that distress associated with HNL reduced with the delivery of a concurrent, intensive HNL treatment program.
Qualitative interview data found several themes raised by patients related to HNL and its impact on distress, function and day to day life. These findings have been used to inform clinical practice, with distress now routinely been monitored in the lymphoedema service.

Many thanks to the patients who shared their experiences and consented to share these images with you

Results- Phase 1

Measure	Baseline Mean (SD)	Week 6 Mean (SD)	Week 22 Mean (SD)	Friedman		Wilcoxon Signed Ranks Test		
				χ^2	p	Baseline vs week 6	Baseline vs week 22	Week 6 vs week 22
Distress (n=10)	5.1 (1.97)	2.4 (1.71)	1.80 (1.75)	11.24	0.004*	.02*	.007*	1.41
EORTC-QoL (n=8)#	64.58 (25.10)	65.62 (29.36)	63.54 (25.95)	0.93	0.63	-	-	-
EORTC- body image (n=10)^	25.55 (24.03)	22.22 (27.72)	19.99 (23.89)	1.87	0.39	-	-	-
EORTC- FOCF (n=10)^	25.00 (22.57)	33.33 (30.43)	31.67 (26.59)	0.92	0.63	-	-	-

*statistically significant p<.05 #higher score = higher QoL (score out of 100)
FOCF- Fear of cancer progression ^lower score = lower problem (score out of 100)

Theme Two: Physical experience and pattern/timing

Categories	n	ref	Example participant quotes
The swelling started....	10	17	“After the operation they must have taken some of the glandsso it created the swelling” P9
....made the swelling worse	8	11	I had surgery, then radiation made it worse after P2
....made the swelling better	10	37	It was more the massage and the exercises that did the most P6
Physical experience of swelling	7	24	I was extremely aware of it, in just talking and moving and I had a habit of just putting my hand up under my chin and it was always there P7

Theme Four: Day-to-day distress

Categories	n	ref	Example participant quotes
Functional impact	7	18	Like you can’t do physical activity because I know after surgery it was so tight and I can’t move one side P5 It just slowed me down P8
Role impact	6	17	My looks (stopped me) volunteering, working at schools breakfast program, doing aqua aerobics, going to church P2 The swelling didn’t affect my lifestyle P6
Impact on others	2	5	They didn’t want to tell me but you got that feeling inside (wife stressed) P5 After this operation when I can’t hear him breathe, a few times I’d wake him up at night to feel that he was ok P10 carer

Theme Five and Six

Theme Five and Six	Subtheme	n	ref
Theme 5: Supports that helped manage distress	Health professionals	8	24
	Family	6	9
	Friends	3	5
Theme 6: Adjustment to a new normal	Ongoing anxiety/distress	4	6
	Downward social comparison	6	9
	Moving forward	6	14

References

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