

Evolving Late-Effects in 15-Year Survivors of Multimodality Head and Neck Cancer Treatment: A Qualitative Study

Introduction:

- Long-term survivorship in head and neck cancer promises to increase as treatments improve and with increasing rates HPV-related squamous cell cancers (which has better overall survival)
- Most survivorship research involves quantitative studies only up to 5-years post-treatment
 - Late-effects of treatment continue well beyond the 5-year mark
- Ultra long term survivors ("ULT," patients surviving >15 years after initial diagnosis) are a growing population that are infrequently studies
- This study uses **Qualitative Research Methods (QRM)** to answer questions about **experience, meaning, and perspective** from the **standpoint of the participant** to learn more about their experience

Materials and Methods:

- Qualitative Research and Narrative Medicine
 - Identify group:**
 - Upper aerodigestive tract cancer patients
 - >15 years from diagnosis
 - Multimodality treatment
 - Conduct Interviews:** in person or telephone, ~30-60 minutes
 - Interview Format:** semi-structured, open-ended questions
 - Transcribe interviews
 - Review and categorize into **codes** and **themes**
 - Grounded theory** → review raw data multiple times, build theory from the "ground up"

Interview Questions:

- What do you **remember most** about your cancer treatment?
- What has been **the most significant persistent problem** related to your cancer and its treatment that you have experienced?
- Tell me about how your **swallowing** changed. When did that occur?
- Tell me about how your sense of **taste** changed. When did that occur?
- Tell me about how your **voice** changed. When did that occur?
- What other things have changed? When did that occur?
- If you could **go back and change one thing**, what might that be?
- What **lessons** has the cancer and the treatment **taught you**?

Results

- 10 interviews conducted – demographics
- 36 codes identified
- 4 overarching themes (listed below with examples)

Patient ID	Current Age	Age at Diagnosis	Years Since Diagnosis	Radiation	Surgery	Chemo
1	68	49	19	Y	Y	N
2	70	55	15	Y	Y	N
3	69	50	19	Y	Y	N
4	76	47	29	Y	Y	N
5	59	32	27	Y	Y	N
6	66	48	18	Y	Y	N
7	82	66	16	Y	Y	N
8	65	49	16	Y	N	Y
9	66	37	29	Y	Y	N
10	93	70	23	Y	Y	N
Avg/total	72 yrs	50 yrs	22 yrs	10	9	1

#1 Existential sense of gratitude

"...as bad as you have it, do an about face and I'm sure you're going to find somebody that has it worse than you do."

"I kind of appreciate being around a lot more...I owe that to the doctors that treated me."

#3 Heightened sense of mortality

"The 6 weeks of radiation. And then, the recovery. And the meetings and the one-year anniversary, and the second year. You just kind of slowly get back into your world. But you are forever changed, because you realize that you're mortal, and most people probably don't have that gift...you've lost that sense that you will live forever."

#2 How cancer affected self-identity (work, activity, family roles)

Laryngectomy patient reflects:
"when I went back to work, I was being harassed at work...people would say 'when are you going to talk again?' ...Then some guys started calling me Darth Vader."

#4

Fatalistic acceptance of potential for additional cancer or complications

"...I am always afraid to ask what might be coming down the road."

ORN misdiagnosed as recurrence:
"So we drove back from Florida with the idea that the cancer was back and I had started the decision that I wasn't going to do anything, that I was going to let it go."



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Results cont.:

- Other interesting sub-themes:
 - Difficulties with obtaining initial diagnosis (83%)
 - Unexpected nature of side-effects and complications (83%)
 - Specific recall of remote conversations (83%)
 - Problems occurring >5 years after treatments
 - Dysphagia (83%)
 - Dental/mandibular (i.e. ORN) issues (67%)
 - Fibrosis (67%)
 - Vascular disease (50%)
 - Late neurological side effects (33%)

Conclusion:

- Many ULT survivors continue to experience persistent and worsening late-effects of their treatment
- Informs how patients navigate their diagnosis, the long-term effect of treatment on self-identity, and a heightened awareness of additional health problems
- Highlights the important concept that while HNC patients may achieve "cure" from their neoplastic disease, many must face the side effects of the curative treatments over their remaining lifetime**
- Helps direct further quality of life research
- Directs counseling for future head and neck cancer patients on the life-long expectations post treatment

References:

Cancer.net; Strojan et al 2017; Florian et al 2019