

Speaking legibly: Qualitative perceptions of altered voice among oral tongue cancer survivors

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ABSTRACT

Objective: Treatment for oral tongue cancer poses unique challenges to restoring and maintaining personally acceptable, intelligible speech. **Methods:** We report how oral tongue cancer survivors describe their speech after treatment in a qualitative descriptive approach using constant comparative technique to complete a focal analysis of interview data from a larger grounded theory study of oral tongue cancer survivorship. Interviews were completed with 16 tongue cancer survivors 3 months to 12 years postdiagnosis with stage I-IV disease and treated with surgery alone, surgery and radiotherapy, or chemo-radiation. All interview data from the main study were analyzed for themes describing perceptions of speech as oral tongue cancer survivors. **Results:** Actual speech impairments varied among survivors. None experienced severe impairments that inhibited their daily lives. However, all expressed some level of concern

about speech. Concerns about altered speech began when survivors heard their treatment plans and continued through to survivorship without being fully resolved. The overarching theme, maintaining a pattern and character of speech acceptable to the survivor, was termed “speaking legibly” using one survivor’s vivid *in vivo* statement. Speaking legibly integrate the sub-themes of “fears of sounding unusual,” “learning to talk again,” “problems and adjustments,” and “social impact.” **Conclusions:** Clinical and scientific efforts to further understand and address concerns about speech, personal presentation, and identity among those diagnosed with oral tongue are important to improving care processes and patient-centered experience.

Key words: Oral tongue cancer, speech, patient experience, qualitative research, cancer survivorship

Introduction

Oral tongue cancer survivorship is an experience that affects women and men of all ages in many societies around the world.^[1-3] The oral tongue is a unique organ, imparting distinct elements of facial appearance and the discrete function of articulation in speech, as well as other functions in speech, eating, and swallowing.^[4-7] The oral tongue

is then linked to fundamentally human activities and to individual identity.^[8] Therapeutic modalities used to treat tongue cancer frequently result in temporary and possibly permanent alterations to speech, affecting the quality of life and functionality in society.^[9,10]

Emerging research defines some effects of both tumor and patient characteristics on overall speech and particular sounds.^[9-15] However, little is known about how oral tongue cancer survivors perceive speech and its implications in their daily lives. Survivor perspectives on speech after tongue cancer treatment may elucidate features important to improved supportive care and help clinicians provide survivors with information about expected recovery trajectories and rehabilitation options. Furthermore, description of survivor experiences of daily life have

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potential to illuminate individual, familial, and sociocultural contexts of life after oral tongue cancer.^[16]

We report a qualitative descriptive focal analysis of interview data set from a larger grounded theory study (termed the main study in the materials and methods section) of the experience of oral tongue cancer survivorship. This focal analysis explores the research question, “What is the experience of altered speech within tongue cancer treatment?”

Methods

Main study methods

The larger study, from which this partial analysis was completed, employs grounded theory design, data collection, and analysis to explore the embodiment of oral tongue cancer survivorship. Grounded theory, a qualitative method linked to symbolic interaction, a grand sociological theory, is particularly well suited to investigation of human psychological and social processes like cancer survivorship.^[17]

Main study recruitment

Potential participants who spoke and read English and were older than 18 years of age were recruited from a single surgical practice in an academic interdisciplinary center for head and neck cancer in the North-Eastern United States. Those patients who accepted the invitation to participate provided consent and were interviewed on that same day. Each participant was offered an interview at a convenient, quiet site. While some participants opted for interviews at their homes, most preferred to conduct the interview around the time of a regularly scheduled appointment for assessment of their tongue cancer.

Main study data collection and management

An open-ended interview was completed by a single interviewer (SHK). The interview began by eliciting the participant’s story of his or her tongue cancer and used probing questions to elicit information based on the participant’s initial responses. Recorded interviews were transcribed by the project manager (GP). The transcripts were checked by the lead investigator (SHK) for accuracy and detail. Transcripts were entered, de-identified, and maintained for analysis in Microsoft Word™ (Microsoft, Redmond, WA, USA) in a secured folder on only two team members’ password protected computers for analysis. Analysis was completed by hand using Microsoft Word™ to manage data and analytic documents.

Ethical conduct and protection of participants

The study was approved by our university’s Institutional Review Board and Clinical Trials Scientific Review and Monitoring Committee. Patients enrolled after providing informed consent to participate in the study and then completed a singled, audio recorded interview. Most but not all participants were both emotionally open and detailed in their interviews; none exhibited distress. Thus, no interviews were stopped for participant distress, and no referrals for additional emotional support were made.

Focal descriptive analysis for diagnostic process

We employed constant comparative technique in a qualitative descriptive approach to achieve our descriptive aim to explain speech concerns among oral tongue cancer survivors. Initial analysis began with reading the entire data set of all 16 interviews collected in the main study. Open coding then began with fracturing data to identify phrases or words relevant to diagnosis.^[17-20] Analysis progressed to axial coding, a step in which we moved open codes into categories of like ideas regarding speech.^[17-19,21,22] The project manager (GP) completed initial coding while the principal investigator (SHK) confirmed all codes to maintain rigor. Constant comparison of fractured data as well as open and emerging axial codes was used to refine and confirm axial codes. We further compared findings with our clinical experience and clinical literature to finalize this analysis. One participant likened speaking after treatment to “speaking legibly.” This malapropism in which legibly is substituted for intelligibly vividly connoted the scrutiny survivors described regarding their posttreatment speech. This *in vivo* code was then selected as the label for the overarching theme describing speech after treatment for oral tongue cancer.

Results

Overview

“Speaking legibly” integrates oral tongue cancer survivors’ experience of altered speech with the effects of surgery and other treatments and additional concentration necessary to regain and maintain acceptable speech in the public and private settings. We narratively detail “speaking legibly” is followed by descriptions of each theme, from “fears of sounding unusual,” “learning to talk again,” “problems and adjustments,” and finally “social impact,” which influences survivors’ thoughts and actions throughout the treatment and recovery process.

Participants

The sixteen patients who had survived oral tongue cancer were at least 3 months and as much as 12 years from

diagnosis. One participant had recurrent oral tongue cancer and two had other nonhead and neck malignancies. Stage at diagnosis ranged from stage I-IV disease. All patients were treated in a single cancer center. The participants ranged in age from 30 to 80 years. Of the 16 participants, eight were women and eight were in marriages or committed partnerships single at the time of interview. Most participants were European Americans ($n = 14$); one participant was European and another was South Asian. No participant expressed explicit financial concerns related to health care or a lack of medical insurance coverage during their interviews.

Speaking legibly

The ability to speak clearly is a function valued in communication and threatened by the diagnosis of oral tongue cancer. One survivor said, "I always use my voice to talk to people" (5; 34-35). "Speaking legibly," as the label describing the theme of speech after treatment for oral tongue cancer, comes from a participant's recollection about her speech after surgery "After my surgery it took me a few weeks to be able to speak legibly" (1; 109-110). Speech plays a significant role in oral tongue cancer experience from the time that a treatment plan is discussed. When survivors who participated in our study recalled their diagnosis, they uniformly expressed related concern for the quality of their speech. Worry regarding future speaking abilities continued until surgery. Many survivors detailed their initial attempts to speak just after surgery. Some were able to speak. These participants reported relief from their worries and uncertainty about the quality of their speech. Others experienced periods of difficulty speaking and being understood, occasionally forcing them to communicate through writing. Within a few weeks of initial treatment, all survivors participating in this study reported being able to hold intelligible conversations. Those whose speech needed improvement often sought the help of a speech therapist or made adjustments to speech themselves. Survivors often found they needed to concentrate on their speech. Many told us they would make mistakes if they were angry, tired, speaking too fast, or pronouncing difficult or unfamiliar sounds. Though some participants perceived their speech as imperfect, all survivors who participated were satisfied with their speech at the time of interview. They further expressed that any changes in their speech did not significantly hinder their abilities at work or in social situations.

Fears of sounding unusual

Worries regarding speech emerged before treatment began and always before any surgery. Importantly, all participants but one accepted the standard of care for treatment that includes surgery. Survivors explained they feared their

"speech would not return to normal" (1; 110-112). In addition to maintaining their "normal" speech, survivors recalled being concerned about losing speech or having a permanent impairment. Many feared they would not be understood in conversations and that their personal and professional relationships would decline as a result: "You fear your relationships, that people won't be able to understand you" 4 (240-41). Others expressed particular concerns connected to hobbies such as singing and jobs such in sales or health care: "Of course in my job I'm talking all day and I sing in the church choir and I canter so I was worried about, you know, would it affect singing" 13 (215-217). In some cases, participants felt the ability to speak was so important that its loss threatened daily life as they understood it: "I spent my whole life giving meetings, public speaking, it was my life really" 14 (67-68). If speech was lost or impaired, life would not be worth living: "If I can't talk I figure juice me up on the table and let me go. Give me a couple of shots and forget about it" 13 (48-49). Once assured that speech after surgery and adjuvant treatment would be possible, this survivor reported feeling a sense of relief: "I didn't want to be where I had to communicate by writing letters or notes. Then I figure I'm home free" 13 (69-70).

Learning to talk again

Immediate postoperative speech varied greatly among survivors. Our participants reported initial attempts at speaking were a turning point in their perceptions of speech after surgery and during adjuvant treatment. Experiences of trying to talk postoperatively influenced participants' worries and feelings of uncertainty about their speech. A survivor who had little speaking recalled her first attempt at speech after surgery "I got back up to my room after the surgery and I think it was my Dad who was there and my stepmother and they asked me a question about how I was doing or something, and I answered them, and they went, 'Yay, she can talk!'" (13; 254-58). Survivors who find they can speak feel relieved. Others experienced edema, pain, and other postoperative signs and symptoms that made speech more challenging. Survivors also struggled to adjust to their "new" postglossectomy tongue: "It's so hard to move your tongue, it's like you're a baby – not even a baby, you have to learn to use that muscle again that you haven't used to 7 months. And it was just really, really hard" (11; 766-769). Several participants relayed how they were unable to speak clearly or "legibly" for a number of weeks: "I couldn't talk to them at first" (6; 278-279). During this time, speech remained a worry yet to be alleviated.

For survivors whose speech could not be understood, writing served as an alternate means to communication

with friends and family during the recovery period. Some found writing tiresome, motivating them to try speaking: “Somebody had given me a white board to write, but I got tired of writing all the long stories and comments” 6 (280-281). Once tongue swelling abated, survivors found they were able to speak again: “I just started trying to talk and when the swelling went down that’s when I was able to communicate then the whiteboard was gone” 6 (282-284.) Over time, survivors’ speech gradually improved, revealing their progress: “I could see the progress I was making” (5; 144).

Postoperative speech determined needs for speech therapy. Survivors who were referred for therapy described performing tongue exercises and make necessary speech adjustments in therapy: “Then a therapist came in to see me, and one of them was— with the exercises with the tongue” 10 (703-704). Speech therapy was frequently noted as having been helpful in regaining normal speech abilities: “Bless the wonderful speech therapist who got me talking with half a tongue very nicely” (5; 35-36). Others were told they did not need speech therapy or prefer to help themselves: “I went to speech therapy here once, but I wasn’t really — I really felt like I could help myself” (4; 254-256). Some constructed their own exercises or methods to evaluate their speech: “Before I even hooked up with her (the speech therapist), I went and brought myself a small tape recorder and I would read a paragraph or a sentence or two out and I would listen to it and if I couldn’t understand the word I keep working on it on my own” (16; 414-418).

Problems and adjustments

Following immediate postoperative recovery, many survivors recognized that their speech is not as precise as it was prior to surgery. A survivor said “sometimes my speech, certain words won’t come out as clear or as precise as they should” (14; 164-165). Survivors pointed to specific instances during which they encounter trouble speaking clearly, such as when pronouncing sibilant sounds or unfamiliar words or those from different languages: “If there are new words, like in anatomy there’s new words — there’s different languages — sometimes my art teacher will mention French or whatever, I have a very difficult time speaking, you know, saying sounds that I’m not familiar with” (4; 422-425). Speech might also be unclear when survivors speak too fast or feel tired: “It got worse at night, when I was tired” (3; 213) or upset: “But if I talk fast or get upset or anything, who the hell knows what’s going to come out” (14; 165-166). Others pointed out that problems were more common as specific times of the day: “Usually by the end of the day it’s (tongue) fine. It’s

more first thing in the morning to midday” (12; 196-197). Finally, some survivors described tongue discomfort as a cause of pronunciation mistakes, describing their tongues as painful, swollen, or cramped: “If I talk a lot or if I’m upset, or there’s any kind of surprise at my job, my tongue cramps up and it hurts — It actually hurts” (11; 903-905). Such discomfort also made it difficult to speak for extended periods of time: “I couldn’t talk for long” (3; 212).

Many survivors spoke of making various adjustments correct problems they identified in their speech. Adjustments included increasing their concentration on speaking: “There are certain sounds that I feel I have to concentrate on a little more and maybe they don’t sound quite as clear” (13; 239-240); speaking more slowly: “If I back up and think about the word and say it slow, it’ll come out” (14;165): And pausing before speaking: “There are times when I have to pause because I have to make adjustments in how I make certain sounds” (6; 496-497). Survivors also told about working harder to enunciate words and how they tried to reshape words by altering the ways in which they used their lips and other structures “I’ve overcome that (lisp) by reshaping my mouth and enunciating as clearly as I can” (10; 727-728).

Social impact

Speaking legibly had social consequences for survivors. Even before surgery, survivors were concerned about how they would be perceived if they might be unable to maintain acceptable speech. “I was embarrassed and worried about how others would view me when I had an obvious speech impediment after surgery” (1; 115-116). Survivors talked about being embarrassed, worried, and self-conscious, feelings which sometimes caused them to change the way in which they view themselves “During that time my self-esteem went down, I was a little depressed, and I’m sure others could see that I was withdrawn” (1; 117-120). Feelings of embarrassment and self-consciousness sometimes resulted in a survivor limiting interactions with friends and family: “People would think that I was really quiet. However, it was more... than quiet — I was very conscious of how I sounded” (4; 267-269). However, others recognized that their self-awareness regarding speech was disproportionate to the actual impediment: “Maybe I didn’t have so much of a problem as I had a consciousness about it” (2; 85-87).

Speech problems created concerns among survivors for their work and careers. These worries were most acute for those working in sales and similar jobs: “I did not want to present to homeowners that I might have to talk to” (2; 87-88).

Self-consciousness was a factor for some survivors as they planned their return to work: “My concern with going back to work too early was speaking, and slurring words” (2; 82-83). Speech then became an important factor in real recovery time and resumption of daily life.

Survivors believed those who knew them best detected speech changes more often than less intimate social contacts. Familiarity with preoperative speech influenced this perception: “My husband does (notice a difference in my speech). And every once in a while the teacher I work with will say, yeah, you sound a little different.” (12; 209-210). Survivors were teased occasionally about unclear speech by close associates, friends, or even family: “My boss would tease me over the phone how funny I sounded” (5; 134-135). Another survivor said: “It’s okay because my kids and my wife make fun of me when the words come out. She tells me I sound like Elmer Fudd (an American cartoon character with a pronounced lisp)” (14; 62-63). Most often, friends and family were supportive, engaging in constructive criticism. Some survivors said they requested that they be told when they spoke too quickly or speech was unclear: “I tell my family, I’m like, ‘If I do (speak too fast), just tell me.’ That way I can fix it, you know. If you don’t tell me, I’ll just keep going. I don’t know whether or not I’m going too fast” (17; 405-08).

Unintelligible speech was spoken of by survivors only in relation to immediate postoperative recovery: “Well, I guess I couldn’t speak because I went food shopping a couple days after and somebody made fun of me, they told me they couldn’t understand anything I was saying” (4; 231-234). The inability to speak clearly at this time often required survivors to repeat themselves numerous times before they could be understood. This temporary loss of understanding proved to be emotionally difficult: “A lot of times people would say ‘What did you say? Can you say it again? Can you say it slower?’ so that was hard” (4; 252-254).

Survivors generally said they perceived greater differences in speech quality than did others: “The pauses to me sound much longer than I’m sure to anybody else” (6; 498-99). Most survivors thought that their speech clarity progressed during and returned to near normal in the sense that it did not interfere with communication “Other people don’t notice anything strange about my speech” (1; 106-107). Where impairments persisted, they were judged sufficient minor that listeners could still focus on what is being said rather than how it sounds. With the exception of one survivor who had recently completed radiotherapy at the time of interview, speech had not interfered with daily life. For this survivor just completing adjuvant treatment,

however, his speech made him feel uncertain about his career: “With all this happening now I don’t know if I’ll ever be able to teach, just with my speech and everything like that, which is fine with me. I’m lucky enough to have a fallback plan with my family business and stuff like that, but uh, it’s kind of disappointing. However, I’m like, hey, you never know, maybe I’ll be able to do it sometime later in life” (16; 439-45).

Survivors usually recognized that their speech was not entirely “normal” after oral tongue cancer treatment. They commonly attributed this alteration to a change in the tongue itself: “I can feel my tongue is not normal still” (1; 107-108). Their speech changed slightly “I might sound like I just talk with a little bit of a lisp” (2; 153-154) and required greater attention for pronunciation and enunciation “I have to really pay attention” (4; 420). Overall, survivors thought cancer and treatment effects were minimal and that their resulting speech was much better than anticipated: “I think the effect (on my speech and speech) has been very minimal” (1; 239). Survivors spoke of being grateful to have survived and maintained the ability to speak despite what they viewed as minor imperfections “there are a few words that don’t come out very well, but I think, ‘I’m here, I’m enjoying life’” (5; 36-37).

Discussion

Main contributions

Our findings suggest that speech is important to the embodied experience of oral tongue cancer survivors. “Speaking legibly” describes survivor perspectives on speech during oral tongue cancer treatment. Participating survivors placed high-value tongue on returning to “normal” speech and the social value of intelligible speech.

The importance of speech as a means of communication and in social interaction renders its loss a salient concern among oral tongue cancer survivors and survivors. Although evaluations of oral tongue cancer survivors’ speech after treatment exist,^[9,10,13,14,23] few studies address the survivor perspective on speech after treatment.^[12] “Speaking legibly” describes the importance of speech to one’s identity and the nature of worries regarding speech outcomes. Patients who struggle with speaking clearly often practice speech and make adjustments, taking an active role in their recovery. Most survivors found that they needed to pay increased attention to speech, and many determined their speech had returned to “normal.” Despite necessary adjustments and concentration on speech, none found their altered speech to be so severe to inhibit their functioning

in society. These findings correspond to the broader qualitative findings reported by Röing *et al.*^[8,16,24] survivors are initially concerned that losing the ability to speak clearly will adversely affect their personal and professional social relationships. This almost uniform concern seems strongly connected to a sense of uncertainty, suggesting the need for well-timed information and supportive care during recovery. Addressing immediate postoperative recovery concerns appears important as well.

Diagnosis of oral tongue cancer begins a process during which survivors gauge whether their speech is “normal.” The process of temporarily losing and then regaining acceptable speech is often protracted and involves some emotional distress. Speech was valued by survivors. Survivors commonly attempted and practiced speaking immediately after surgery and beyond. They often took initiative themselves before seeing a speech therapist. Such actions suggest that some survivors are not willing to “wait and see” if their speech will improve, preferring an active role in its improvement. Survivors also reported not returning to work until they deemed their speech acceptable. While recent quantitative work to measure speech intelligibility provides important insight for nurse, physicians, and other clinicians whose primary focus is not speech,^[9,14] understanding patient and survivor perspectives is a critical to improving and increasing the quality of care for patients diagnosed and treated for oral tongue cancer as it is for those with other oral cavity cancer diagnoses.^[8,16,24]

Limitations and global implications

Our analysis of altered speech among oral tongue cancer survivors is a descriptive component of a larger, retrospective grounded theory study of survivorship in oral tongue cancer. Our findings are limited by a retrospective recollection of speech during treatment, a single interview for data collection, and descriptive analysis. In addition, they are drawn from individuals treated at a single center in the United States. Cultural nuance in cancer treatment and survivorship mandates a future inquiry into the experience in other cultures around the Pacific Rim and across societies where the tongue and other oral cavity cancers are a health concern.^[13,16] Thus, our findings are useful in highlighting that experience of changed speech during tongue cancer treatment and other aspects of survivorship require further qualitative and quantitative study and additional focus in clinical care. While our findings reinforce current general supportive nursing interventions and interdisciplinary practices, we believe they underscore the need for future further prospective explorations of speech and other

expressions of embodiment and appearance for oral tongue and other oral cavity cancer survivors.

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