

# Living in limbo: Being diagnosed with oral tongue cancer

Genevieve Philiponis<sup>1</sup>, Kelly M. Malloy<sup>2</sup>, Sarah H. Kagan<sup>3</sup>

<sup>1</sup>School of Medicine, Temple University, Philadelphia, PA, <sup>2</sup>School of Medicine, University of Michigan, Michigan, <sup>3</sup>School of Nursing, University of Pennsylvania, Philadelphia, PA, USA

**Corresponding author:** Sarah H. Kagan

E-mail: skagan@nursing.upenn.edu

Received: December 09, 2014, Accepted: April 08, 2015

## ABSTRACT

**Objective:** Oral tongue cancer presents clinical challenges to effective diagnosis that affect patient experience. Patient experience of the diagnostic process is poorly described, making opportunities for nursing intervention unclear. **Methods:** We qualitatively describe, using constant comparative analysis, oral tongue cancer diagnosis using data from a larger grounded theory study of oral tongue cancer survivorship. Using constant comparative analysis — in keeping with the methodology of the main study — we analyzed 16 survivor interviews for themes explaining the patient experience of oral tongue cancer diagnosis. **Results:** We termed the broader diagnostic process “living in limbo.” This process includes the themes describing the peri-diagnostic process itself — “self-detected lesion,” “lack of concern,” “seeking help,” “not a straightforward diagnosis,” and “hearing the diagnosis.” Entry

into treatment concludes “Living in Limbo” and is described by the theme “worry and trust.” **Conclusions:** Our findings are limited by retrospective interviews and participant homogeneity among other features. Future research with prospective designs and diverse groups of people at risk for and diagnosed with oral tongue cancer, as well as targeting those who have had negative biopsies with no eventual diagnosis of oral tongue cancer, will build on our findings. Further, study of patient experience in other sociocultural context and healthcare systems is needed to inform nursing science and practice. Finally, “living in limbo” suggests that clinician and public education about oral tongue cancer diagnosis is needed.

**Key words:** Oral tongue cancer, cancer diagnosis, patient experience, grounded theory, qualitative research

## Introduction

Oral tongue cancer is a relatively uncommon malignancy worldwide.<sup>[1]</sup> Investigations of screening and detection practices have aimed to improve timeliness of diagnosis and diagnose cancer at an earlier stage.<sup>[2-4]</sup> Though current investigations reveal some plausible explanations for delays in accurate diagnosis, little available evidence details the broader experience of diagnosis from the patient’s perspective.<sup>[5-7]</sup> Patient’s perspectives and experiences might offer greater insight to frame clinical problems such as delays or missed diagnoses

and opportunities to improve supportive care.<sup>[8-10]</sup> Description of and reflection on experiences like being diagnosed with cancer, although retrospective, potentially illuminate particular medical processes, and larger sociocultural contexts in which people act on health concerns.<sup>[11,12]</sup>

We report a descriptive analysis of an interview data set from a larger grounded theory study (termed the main study in the materials and methods section) on the experience of oral tongue cancer survivorship. In this focal analysis, we explore the research question “What is the process of oral tongue cancer diagnosis?”

## Methods

### Main study methods

The larger study employs grounded theory design, data collection, and analysis to explore the embodiment of oral

Access this article online

Quick Response Code:



Website: [www.apjon.org](http://www.apjon.org)

DOI:  
10.4103/2347-5625.158021

tongue cancer survivorship. Grounded theory, a qualitative method founded in the symbolic interaction theory of sociology, is particularly well suited to investigation of human psychological and social processes like cancer survivorship.<sup>[13]</sup>

### **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. As a result no interviews were stopped and no referrals for additional emotional support were made.

### **Focal descriptive analysis for diagnostic process**

Using constant comparative technique to achieve our descriptive aim, 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.<sup>[13-16]</sup> Analysis then progressed to axial coding where we collapsed open codes into categories of like types of words, phrases, and ideas to create categories related to diagnosis.<sup>[13-15,17,18]</sup> One team member (GP) completed initial coding and another (SHK) confirmed both open and axial codes to support achieving rigor within this analysis. Constant comparison of the data, specifically comparison of text passages within and across interviews, was used to refine, expand, and verify axial codes. These axial categories were compared with data and open codes to selectively code for the diagnostic process. We further compared findings with clinical experience and relevance to existing literature to finalize the analysis. A verbatim statement from a participant, "living in limbo," was selected to label the overarching diagnostic theme.

## **Results**

### **Overview**

"Living in limbo" describes the overarching process of being diagnosed with oral tongue cancer as revealed in data collected from our group of participants. We report our findings by first providing a summary of the "living in limbo" process. The peri-diagnostic process is described in the themes "self-detected lesion," "lack of concern," and "seeking help." Diagnosis is describing in two themes "not a straightforward diagnosis" and "hearing the diagnosis" while entry into treatment concludes the overarching process and is captured in the theme "worry and trust."

### **Participants**

The sixteen patients who had survived oral tongue cancer were at least 3 months and as much as 12 years from diagnosis. No patient had a second head and neck malignancy; although one had recurrent oral tongue cancer and two had other non-head and neck malignancies diagnosed. Stage at diagnosis ranged from stage I to stage IV disease. All patients were treated within the same center. The participants ranged in age from 30 to 80 years. Of the 16 participants, eight were women, four were single (e.g., un-partnered or divorced), and the others were in long-term relationships (e.g., marriage or other partnerships) at the time of interview. While most participants were European American ( $n = 14$ ), one 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.

### ***The process of being diagnosed with oral tongue cancer: “Living in limbo”***

To quote one participant, the process of being diagnosed with oral tongue cancer is one of “living in limbo.” This survivor said “I kind of lived in limbo from the 17<sup>th</sup> until I saw the head and neck surgeon” in describing how it felt to be diagnosed with oral tongue cancer (6; 156-157). This individual’s expression echoed those all participants who expressed a sense of uncertainty and ambiguity as they journeyed remarkably similar paths. These paths began with finding something amiss with their tongues and ended in the diagnosis of oral tongue cancer. Diagnosis of oral tongue cancer was a defining experience for every participant. They recalled it with great precision to be “the beginning of an experience I’ll never forget” (4; 103-04) and some remembered dates and other details clearly: “I could probably tell you exact dates, and it’s amazing how... it just sticks in your mind” (6; 99-101). Even a participant who seemed to diminish the diagnosis said: “I’m not gonna be here forever — I mean I’m not your age now, I used to be your age, but you know — things are gonna happen to me as I get older” (2; 166-169).

“Living in limbo” began uniformly with identification of a lesion. Notably, all of our participants detected this lesion themselves. “Living in limbo” ended, often after many “blind alleys” of complaints of persistent lesions and negative biopsies, with a diagnosis of oral tongue cancer and the sub-theme “worry and trust” which describes entry into treatment. Our participants often noted in retrospect that the self-detected lesion was accompanied by a lack of concern on the part of our participants. After some time passed and the lesion persisted or worsened, all participants first sought help from a dental care provider, most often their general dentists. Seeking help from their dentists created a sense of concern. It also resulted in a series of referrals and biopsies. Several participants experienced multiple biopsies with negative or inconclusive results. Eventually, the oral surgeons to whom these participants were referred delivered a positive biopsy result and conferred the diagnosis of oral tongue cancer. That diagnosis was met with disbelief on the part of the patient; disbelief at the cancer diagnosis; and even disbelief that an entity of tongue cancer exists. The oral surgeon then referred the participant to a head and neck surgeon who initiated the treatment plan. This plan involved surgery for all but one participant. As they recalled the plan, most participants accepted it with few questions. Many participants revealed that trust in clinicians and the information they provided, when and how to consider a second opinion, and worry exhibited

by themselves and their loved ones were elements of their entire experience, from the time of seeking help through diagnosis.

### ***Self-detected lesion: “Something felt funny”***

All our participants described a lesion that signaled the beginning of “living in limbo.” They described the lesion variously as an “ulcer,” “sore tongue,” “growth,” “little bump” or “blister” as in “I went to our dentist and I had a blister on the left side of my tongue” (9; 68-69). A mildly uncomfortable sensation was present for some “like a little tongue ulcer you get if you eat too much tomato sauce” (2; 46-47). Others experienced constant soreness and recalled “not feeling comfortable. I felt like I had bitten the side of my tongue” (6; 102-103). Still others spoke of discomfort only while engaging in activities that involved their tongues. One participant expressed this discomfort as being “a little painful when I ate, but otherwise I didn’t feel anything at all” (9; 72-73). Our participants investigated the site of discomfort or pain in a mirror. Many described what they saw in terms that would draw the attention of clinicians experienced in oncology care: “Under the tongue, on the left side, was a growth that looked like this. It was level with the tongue at this point, but then it rose slightly off the tongue, and this was a ragged edge. And I didn’t know what it was” (10; 136-139). Another reported “something felt funny. I looked, you know, in the mirror at the side of my tongue and I could see this little plaque-like, white plaque-like thing” (13; 163-165).

### ***Lack of concern: “Didn’t think much about it”***

The vast majority of our participants were initially unconcerned about the discomfort, pain, and visible lesions they experienced. However, one participant whose mother had died from metastatic oral tongue cancer was the exception to this rule; she was immediately concerned by the tongue lesion. Thus, all but this single participant had no notion that the lesions they found might be malignant. As a group, they uniformly recalled no initial concern at the sight of a lesion and said repeatedly that they gave it little thought: “I didn’t think much about it” (9; 69-70) and “well, I wasn’t thinking about it” (10; 142). Some said that they thought that it would resolve spontaneously, while others decided to wait to see if it resolved, assuming that “this will pass” (6; 103-04). Some also tried treating it themselves with over-the-counter oral care products. One recalled “(letting) it go for a while and went out and got like Anbesol™ (an over the counter oral anesthetic liquid), things like that, thinking it was something that I could fix” (12; 72-74). Despite an express lack of initial concern from most participants, most were equally careful about what they ate and even how they

spoke. They seemed to be trying to avoid irritating what was often a sensitive lesion: “[I] was babying it, was very careful when I was eating, but it wasn’t getting any better” (6; 104-105). Nonetheless, they all ultimately discovered that the lesion did not resolve: “It wasn’t going away” (2; 48-49). For many, the lesion became more symptomatic: “It was starting to feel worse instead of better” (6; 113).

### *Seeking help: “I saw my dentist”*

Most participants sought out their dentists initially for help with the persistent lesions: “I made an appointment with a local dentist since I needed to have my routine cleaning anyway” (1; 14-16) and “it started out as a toothache, so I saw my local dentist” (2; 39). Other participants first visited primary care physicians or periodontists, as these two participants stated: “I had a sore tongue, and a little bump — and I pointed it out to my periodontist.” (3; 53-55) and “I made an appointment with my primary care physician and saw him” (10; 143-145). Participants recalled their dentists demonstrating concern in most cases. The typical strategy employed by the dentist was to send the patient to an oral surgeon for biopsy. Some participants remembered immediate referral for biopsy if the dentist was very concerned. Others recalled dentists and primary care physicians asking colleagues for a second opinion, implying, but not confirming, uncertainty. Some participants recollected thinking that the initial clinician who assessed the lesion was not particularly concerned about it, recommending a period of observation and even topical treatments with follow-up should the lesion prove persistent.

### *Biopsy and diagnosis: “Not a straightforward diagnosis”*

Biopsy of the now concerning lesion was directed by the oral surgeon for most participants. Only those participants already familiar with oral tongue cancer or already being treated by an oral surgeon for another problem proceeded directly to a head and neck surgeon for biopsy. At this point, concern about the biopsy varied for participants. Some remarked on their awareness of their bodies and the sense that something was wrong. Others reported believing that the biopsy was just a precaution taken by conscientious clinicians. Many responded to the oral surgeon’s initial reactions on assessing the lesion. Concern on the part of the oral surgeon predictably elicited concern from participants. Report of the biopsy results became critical to participants’ memories of “living in limbo.”

Imbedded within “biopsy” is a trajectory that is circuitous for some participants, making diagnosis often recursive

and not at all straightforward for patients. Negative biopsy results, generally for lack of sufficient tissue, complicated diagnosis in some instances. Two participants offered common results: “The biopsy, as it was, turned out to be ok” (3; 58-59) and “He took a biopsy, sent it out, and when it returned it was negative” (9; 78-79). Sometimes there was reassurance offered on the basis of non-malignant results” “they told me that it was a benign lesion, don’t worry about it” (13; 183-184). Three participants had stories of negative biopsies and several felt they were “going to doctor after doctor” in light of their persistent lesion. Undergoing a larger biopsy was one option after negative results: “... took another biopsy, a larger one — I think I had five stitches in my tongue” (9; 81-83). Others were observed over time, only to return for one or more successive biopsies when the lesion did not resolve: “I saw Dr. G. for a year with numerous biopsies” (3; 73). For other participants, a changed or worsened appearance led to new biopsy: “About 4 months later it healed but it was, um, it got a little hard on the tongue. And I saw my other doctor and he was like, “I think you have leukoplakia”” (11; 190-192). Some participants became very active in monitoring the lesion that eventually was diagnosed as oral tongue cancer: “I would periodically look at it, so after I looked at it here I said, “This doesn’t look like it used to look”” (13; 187-88).

### *Receiving the diagnosis of oral tongue cancer: “Hearing the diagnosis”*

Participants’ reaction to hearing the positive biopsy results varied. Some were relatively unsurprised: “Deep down when the blister didn’t disappear, I really wasn’t that surprised that I heard the diagnosis because it had been nagging at me subconsciously” (9; 94-97). Participants sometimes remembered believing that the clinician’s demeanor indicated “bad news”: “And I returned a week later, he didn’t have to say a word. I could see it in his face. He just looked so somber and then he told me that I had cancer” (9; 86-89). Others reflected on a family history of cancer and described feeling less shocked to hear results indicating cancer: “I was, I think the reason that I was sort of a little bit prepared of it being cancerous is because my entire family died of cancer. My — from my godmother, my father’s mother, my father, my mother, my brother — they all died of various, uh, organ cancers.” (9; 116-120). For participants who had previous experience with cancer, merely a request to return to the oral surgeon’s office confirms a positive biopsy: “The receptionist said to me, “Can you come in?” and I said, “Well yes I can but you’ve already given me my diagnosis”” (13; 199-200).

Conversely, the majority of participants described being shocked by the cancer diagnosis: “I couldn’t believe it.” (1; 22) and “That’s how taken out at the knees I was with the news” (6; 404-05). Even though they indicated they expected a serious diagnosis, the diagnosis of cancer exceeded those expectations: “I knew it wasn’t good, but I wasn’t expecting that” (6; 127-28). Some experienced such disbelief that the diagnosis felt surreal. Others described being overwhelmed: “I was just semi-hysterical about it. And you know, here I am, I’m in a brand new place, somebody I don’t know at all” (13; 169-72) and “The news was unbearable, devastating almost” (8; 28-29).

No matter what their emotional response, participants experienced a tremendous sense of upheaval upon hearing the diagnosis: “You hear the word cancer and your whole world changes instantly” (6; 129-30). They expressed uncertainty about being able to overcome cancer and wondering if it will debilitate or kill them. Several participants stated they were unaware that tongue cancer is even a real disease: “I never heard a tale of anything like this cause, I live in the country, you know.” (8; 96-97). They commented that this revelation were the reason they chose to participate in this study; many wanted to tell their stories so that others might learn. Many commented that their personal lack of awareness of oral tongue cancer was a source of great anxiety because the uncertainty it engendered.

Part of hearing the diagnosis is referral to a treating oncologist. Many participants recalled being reassured by the oral surgeon that a head and neck surgeon will provide the best possible care: “He sent me down here to Dr. C. and that’s where things started” (12; 87-88). A few participants had to choose between two institutions and sometimes considered factors like distance from home: “And I said, “Well there’s nothing around here?”” (10; 166-67). Most expressed a desire to be treated by “the best” clinicians they could find. A participant recalled his conversation with his oral surgeon: “He said to me, “You want the best?” How do you answer that one? It was answered for me” (10; 168-69). These individuals stated they were willing to travel to receive state of the art treatment. Before leaving the oral surgeon’s office on the day of diagnosis, each participant was provided with information to make an appointment with the head and neck surgeon: “I made an appointment as soon as I could” (1; 28). Family members sometimes assisted with scheduling and participants recalled these efforts clearly: “My daughter... she said, “Dad, let me handle it”” (10; 235). Some also felt obtaining the initial appointment was challenging: “I couldn’t get any satisfaction from anyone down there” (10; 179-80). Most,

however, remembered getting an appointment within a week or two: “She got me an appointment in 2 weeks” (10; 185-86). Often the oral surgeon’s staff facilitated these appointments for patients.

Despite understandable shock and distress, many participants remembered being able to remain composed for some time. Some felt they were too shocked initially to react directly to the diagnosis. Others felt responsibility to “hold it together” to drive home: “I have my 7-month-old baby with me, I need to keep it together so that I can at least drive home with him” (1; 51-52). Once at home, some recalled breaking down and crying: “We made it home, and then I collapsed and we both discussed the day’s affair” (9; 102-03). Others were more stoic in their reactions “I never cried. . . I still haven’t cried about this.” (12; 92-94).

Participants with partners and spouses typically shared the diagnosis with their partner first “I didn’t tell anybody. I — the only person I told was my husband when I came home” (6; 146-47). Many felt a need to protect their children or even their parents, from hearing the diagnosis: “We actually didn’t tell our families right away.” (1; 54-55) and “I didn’t want to tell the kids” (6; 148). Family members were more likely to be told the full story of the diagnosis after a treatment plan had been established: “I needed to be able to say, ‘I have tongue cancer, but this is what’s going to happen.’” (6; 150-51) and “I was trying in the beginning, when I wasn’t sure what I was doing, I was trying not to even tell her about it” (13; 107-09).

Uncertainty characterized the time — no matter how brief — between the diagnosis and the appointment with the head and neck surgeon: “It just was a very difficult thing to get through the weekend cause I — I really didn’t know what to do” (6; 141-43). Many participants simultaneously wondered why they had developed oral tongue cancer, seeking an explanation for their predicaments: “I still, you know, wonder what other factors were involved” (6; 383-84). They recalled learning about oral cancer’s association with tobacco and alcohol use: “I’ve never had a cigarette or drink in my life and I kept thinking, why me, you know?” (8; 74-75). Participants spoke of fearing chemotherapy, radiation, and tube feeding that they believed might be necessary: “I was also worried that I may need radiation.” (1; 37-38) and “We were afraid that I’d have the tube feeding, and you know how bad it could be” (4; 150-51141). For those intervening weeks, some felt as though they were “living in limbo” and were plagued by nervousness, anxiety, and unrest, “I kind of lived in limbo from the 17<sup>th</sup> until I saw the head and neck surgeon” (6; 156-57). Another said “you’re really afraid for your life” (4; 298-99).

### **Entering cancer treatment: “Trust and worry”**

Trust and worry intertwine throughout the process of “living in limbo,” beginning with “getting concerned” and becoming influential as a treatment plan is proposed. Support from a friend or family member commonly marked the initial appointment with the head and neck surgeon: “A friend offered to drive me down to see the head and neck surgeon for my first appointment” (6; 157-58). Another common theme was overwhelming information: “And he started giving me statistics and I said “stop” — too much information” (4; 110-12). Receiving a treatment plan becomes the center point of the visit: “He said, uh, that it would have to come out, and I think he described it — he would cut it out, but then I would have to have reconstructive surgery of the tongue” (10; 192-95).

Participants typically agreed to treatment, although reaction varied and sometimes involved dispute and a second opinion: “And I thought that was real drastic, surgery on my tongue” (3; 68-69) and “Don’t be insulted, but everything you tell me, I’m going to run by my oncologist” (13; 230-31). Others are satisfied, putting full trust in the surgeon and the treatment plan: “I did not want to be faced with having to make any other decision. I just wanted it handled, so I didn’t want a second opinion” (6; 398-400). Most reported sharply reduced uncertainty: “I put myself in your hands, take care of it and I don’t want to think about any more of it” (6; 636-38). Many engaged in “mental pep talks:” “I just thought, we’ll take care of this, we’ll get over it” (12; 95); “Do it, fix it, that’s it, let’s go” (5; 383-84); and “Figured I’m gonna fight this thing you know and I’m gonna go on and really get it” (8; 71-72). One participant even projected coping with potential future recurrent disease: “And so we cope with it. When it comes back, well, we cope again” (9; 276-77). As surgery is scheduled, some ask for the earliest operative date because they are eager to get the lesion out and be done with surgery: “I said, ‘You don’t have anything before? I wanted it over and done with and out’” (12; 104-06).

Many participants worried about what would happen during and after treatment. They expressed retrospective concern over their appearance and ability to eat and speak after surgery, though most later found their worries were greater than reality. Those worries could be extreme: “when he told me the radical surgery he wanted to do, I said “Are you crazy?,” and um, like — I’m gonna be like Frankenstein?” (11; 61-62). Participants were not always satisfied with the information provided about their disease and treatment: “I had called the NCI to get information and I got a booklet on head and neck cancer — but there wasn’t really anything in it about tongue surgery” (3; 111-13). They

sought information from other sources and failure to find such materials was reported as frustrating and dissatisfying: “I know that there were times when I, I felt a bit frustrated about unanswered questions” (3; 123-124).

Beginning with the initial detection of the lesion, participants described relationships with dentists and surgeons as a source of trust in people and treatment. A growing sense of trust from the initial referral forward seemed to limit doubt: “I trusted that the oral surgeon — you know, and I think that’s — some of that’s your comfort level with the doctor” (6; 400-02). Some participants who had battled another cancer before being diagnosed with tongue cancer had ongoing relationships with other oncologists on whom they relied for advice: “She’s saved my life once and you know, I trust her” (13; 231-32).

## **Discussion**

### **Main contributions**

Our description of the process of being diagnosed with oral tongue cancer is novel and provides unique insight into several dimensions of survivorship experiences. First, “living in limbo” underscores the sense of precariousness and uncertainty of diagnosis. Second, the process speaks to the multiple steps and many interactions often necessary in a cancer diagnosis. Third, our description emphasizes that for our participants, all of whom had health care coverage in the American healthcare system; more than one referral was involved in completing diagnosis and outlining treatment. Finally, “living in limbo” revealed the intersecting matters of trust and worry in undergoing diagnostic procedures and hearing the ultimate diagnosis.

“Living in limbo” as a human experience details variability of embodied knowledge of one’s own health and vulnerability engendered by interaction with the formal, allopathic health care system. The transition from a self-detected lesion to oral tongue cancer was circuitous, showing the innate response of self-treatment and monitoring as well as rising concern when the lesion does not improve or resolve. Combined with the almost universal surprise among our participants that oral cancer was an actual disease, the actual recognition of worrisome lesions suggests a need for targeted public health education on oral cancer. Further research using qualitative and mixed methods will expand understandings of personal conceptions of oral health, knowledge of oral health concerns, and self-monitoring behaviors. Specifically, the burgeoning epidemic of human papilloma virus infection mandates focused research and concurrent public health

education to address parallel risk of oral tongue and other oral cavity cancers.<sup>[19]</sup>

Being diagnosed with oral tongue cancer is not a straightforward and direct experience. Our only participant who was referred directly to a head and neck surgeon for diagnosis was a woman with previous knowledge of the disease. Most participants endured two or three “steps” before hearing a diagnosis and treatment plan. These steps, or levels of referral, included a primary care assessment, an intermediate level of the oral surgeon, and final referral to a head and neck surgeon. This set of referrals implies that there might be missed opportunities for early detection and timeliness of initiating treatment. With adequate primary care clinician education and knowledge of oral cancer, an unnecessary intermediate “step” in the diagnostic process may be avoided, thus allowing the patient to be directly referred to a head and neck surgical oncologist for more timely care. Our findings suggest the need for further investigation of diagnostic experiences to examine the knowledge and actions of primary care physicians, dentists, and nurse practitioners during diagnosis and their impact on patient outcomes. Education of clinicians and the public is necessary to insure optimal early detection and adequate treatment. Specific exploration of the roles nurses can play in public education, screening and early detection, and supportive education and intervention during diagnosis and initiation of treatment is certainly necessary.

We gained insight far beyond what we could convey here into the emotional, psychological, and spiritual journey of being diagnosed with an uncommon disease and embarking on treatment. Particularistic glimpses into the lives of survivors as people with full, varied lives allowed us to see better the people we treat and to ask more focused and empathic questions of them. We cannot overstate the value of qualitative research in creating empathy among nurses and other clinicians.<sup>[20]</sup> Our findings suggest the value of eliciting diagnostic experiences in systematic explorations within specific cancers and in clinical practice where the journey to diagnosis mandates individualized nursing assessment and supportive intervention.

### Limitations and global implications

Our analysis of the process of being diagnosed with oral tongue cancer is a descriptive component of a larger grounded theory study of survivorship. Our findings are limited by retrospective recollection of diagnosis, particular dimensions of homogeneity among our participants and single interview data collection. Our findings are drawn from participants who were generally well educated and

had ample access to healthcare. Their diagnostic referral patterns draws into question the concept of access to care and whether there is such a thing as “too much” access. Some diagnoses might have been delayed because of additional referrals, watchful waiting, or repeated biopsies. These are elements of healthcare that may, in the American context, result from better than average access to healthcare. Poorer, ethnically diverse populations with limited health care access may have more direct diagnostic processes because of circumscribed or limited access to dental and health care providers. Further research with diverse populations may better illuminate influences on variations and disparities in diagnostic processes. Further, similar inquiry in other sociocultural contexts and different healthcare systems along the Pacific Rim and around the world is needed as are studies that are prospective and follow individuals through the experience of screening, diagnosis, and surveillance.

## Acknowledgments

The Edwin and Fannie Hall Gray Center for Human Appearance at the University of Pennsylvania Small Grants Program.

## References

1. Jemal A, Bray F, Center MM, Ferlay J, Ward E, Forman D. Global cancer statistics. *CA Cancer J Clin* 2011;61:69-90.
2. Cruz GD, Shulman LC, Kumar JV, Salazar CR. The cultural and social context of oral and pharyngeal cancer risk and control among Hispanics in New York. *J Health Care Poor Underserved* 2007;18:833-46.
3. Cruz GD, Ostroff JS, Kumar JV, Gajendra S. Preventing and detecting oral cancer. Oral health care providers' readiness to provide health behavior counseling and oral cancer examinations. *J Am Dent Assoc* 2005;136:594-601.
4. Warnakulasuriya S. Global epidemiology of oral and oropharyngeal cancer. *Oral Oncol* 2009;45:309-16.
5. Scott SE, Grunfeld EA, Main J, McGurk M. Patient delay in oral cancer: A qualitative study of patients' experiences. *Psychooncology* 2006;15:474-85.
6. Scott SE, Grunfeld EA, McGurk M. Patient's delay in oral cancer: A systematic review. *Community Dent Oral Epidemiol* 2006;34:337-43.
7. Silver, K., Bauld, L., Warnakulasuriya, S. and Day, R. (2009) *The Experiences of Younger Oral Cancer Patients in Scotland: From Self-diagnosis to Treatment (Final Report)*. Other. Centre for the Analysis of Social Policy, Bath, United Kingdom. [http://www.bath.ac.uk/casp/assets/Oral\\_Cancer\\_Study\\_x2008x.pdf](http://www.bath.ac.uk/casp/assets/Oral_Cancer_Study_x2008x.pdf)
8. Röing M, Hirsch JM, Holmström I. The uncanny mouth-A phenomenological approach to oral cancer. *Patient Educ Couns* 2007;67:301-6.
9. Röing M, Hirsch JM, Holmström I, Schuster M. Making new meanings of being in the world after treatment for oral cancer. *Qual Health Res* 2009;19:1076-86.
10. Kilbourn KM, Anderson D, Costenaro A, Lusczakoski K, Borrayo E, Raben D. Feasibility of EASE: A psychosocial

- program to improve symptom management in head and neck cancer patients. *Support Care Cancer* 2013;21:191-200.
11. Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: Qualitative study. *BMJ* 2004;328:1470.
  12. Crossley ML. 'Let me explain': Narrative emplotment and one patient's experience of oral cancer. *Soc Sci Med* 2003;56:439-48.
  13. Corbin J, Strauss A. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks, CA USA Sage Publications; 2014.
  14. Boeije H. A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Qual Quant* 2002;36:391-409.
  15. Glaser BG. The constant comparative method of qualitative analysis. *Soc Probl* 1965;12:436-45.
  16. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nurs Health Sci* 2013;15:398-405.
  17. Thorne S. Data analysis in qualitative research. *Evid Based Nurs* 2000;3:68-70.
  18. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77-101.
  19. Leemans CR, Braakhuis BJ, Brakenhoff RH. The molecular biology of head and neck cancer. *Nat Rev Cancer* 2011;11:9-22.
  20. Kearney MH. Levels and applications of qualitative research evidence. *Res Nurs Health* 2001;24:145-53.

**How to cite this article:** Philiponis G, Malloy KM, Kagan SH. Living in limbo: Being diagnosed with oral tongue cancer. *Asia Pac J Oncol Nurs* 2015;2:242-9.

**Source of Support:** The Edwin and Fannie Hall Gray Center for Human Appearance at the University of Pennsylvania Small Grants Program.  
**Conflict of Interest:** None declared.