

ORIGINAL ARTICLE

Chinese Tongue Cancer Survivors' Perspectives  
One Year Post-Partial Glossectomy

Zou Yanhui<sup>a</sup>, Yanqun Li<sup>b</sup>, Xiao Zhou<sup>\*c</sup>, Jianjun Yu<sup>d</sup>, Yanping Xie<sup>e</sup>, Li Li<sup>f</sup>, Caiyun Ouyang<sup>g</sup>, Zan Li<sup>h</sup>,  
Mei Gu<sup>i</sup>, Elisabeth M. Hicks<sup>j</sup>, Sally L. Maliski<sup>k</sup>



Zou Yanhui

a, c, d, e, f, g, h & i Hunan Cancer Hospital, The Affiliated Cancer Hospital Of Xiangya School Of Medicine Central

b RN, Second Xiangya Hospital School of Medicine of Central South University

j & k School of Nursing University of California, Los Angeles

ABSTRACT

**Background:** Tongue cancer is the most common form of oral cancer globally. Treatment for tongue cancer has become more effective, but there are heavy functional and aesthetic sequelae that affect quality of life. Assisting patients to attain a satisfactory quality of life post-operatively requires health care providers have an understanding of how these sequelae are perceived by the patients. Little is known about how people in China perceive and manage the sequelae of tongue cancer surgery. **Objective:** To understand how people in one province in China perceive and manage the sequelae of surgery for tongue cancer.

**Methods: Population:** Sixteen participants from a provincial hospital in China who had partial glossectomy and free thigh flap reconstruction at a major Chinese cancer center were enrolled in the study. All were men. Semi-structured interviews were conducted with participants one year following their surgery. Interviews were conducted and transcribed in Mandarin. Analysis was conducted using modified content analysis techniques to identify and describe major categories.

**Results:** We identified several categories related to functional alterations, appearance changes, social impacts, and management of the sequelae. These include changes in eating, speech, decreased shoulder mobility, facial appearance; the impact of these changes on social activities; and accommodations made such as use of Traditional Chinese Medicine and changes in eating patterns.

**Conclusion:** The support of family and friends was important to the recovery process. Adaptations to the treatment sequelae allowed these participants to maintain adequate food intake, resume some daily activity, and manage discomfort. Physical therapy may alleviate shoulder weakness and numbness post-surgery.

**Keywords:** Tongue cancer; quality of life; glossectomy; reconstruction, China, survivor; Traditional Chinese Medicine

**\*Corresponding Author:** 283 Tongzipo Road, Yuelu District, Changsha, 410013, Hunan, P.R. China. e-mail: [cccdon@sina.com](mailto:cccdon@sina.com)

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## Introduction

Data compiled from regional registries in China from 2009 to 2010 reported oral cancer in 1,171 in men and 770 in women. The age standardized incidence rates were 2.1 per 100,000 people for men and 1.2 per 100,000 people for women with a male to female ratio of 1.7 (de Camargo Cancela, de Souza, & Curado, 2012). Similar incidence was reported in 2008. Tongue cancer is the most common oral cancer site globally, but with much geographic variation. However there is a paucity of information on the epidemiology of oral cancer in developing countries (Moore, Johnson, Pierce, & Wilson, 2000). In Asia, the most common form of oral cancer is tongue cancer which is strongly related to smoking and alcohol consumption (de Camargo Cancela et al., 2012; Krishna Rao, Mejia, Roberts-Thomson, & Logan, 2013). The chewing of areca nut and tobacco is also a cause of oral cancer in China, although it is not as common as in parts of southern Asia or Oceania (de Camargo Cancela et al., 2012). China has a lower incidence of oral cancer than many other countries in Asia (Krishna Rao et al., 2013). However, as tobacco use becomes more prevalent in China, this can be expected to increase.

As treatment for tongue cancer has become more efficient and effective in China, more Chinese people are surviving tongue cancer. However, there are heavy functional and aesthetic sequelae associated with the most commonly used surgical intervention, glossectomy with free flap reconstruction. The physical alterations caused by the surgery can seriously affect an individual's ability to speak and eat as well as alter his/her facial appearance. These changes lead to limitations in many areas of the survivor's life (Dziegielewski et al., 2013; Eades, Chasen, & Bhargava, 2009; Hartl et al., 2009; Kammer & Robbins, 2011; Schuster & Stelzle, 2012; Semple, Dunwoody, Kernohan, McCaughan, & Sullivan, 2008).

Chinese people with tongue cancer experience specific cultural challenges which affect recovery. In China, cancer is viewed as a death sentence despite improving survival rates. Culturally, family members are expected to provide all of the support and care for the survivor during recovery. Family members have a moral obligation to care for any family member who is ill. Also, meal times are important for social interaction and the facial, eating, and speaking changes caused by tongue cancer intervention can interfere (Bell, Lee, &

Ristovski-Slijepcevic, 2009; Chan, Hon, Chien, & Lopez, 2004; Chen, Miaskowski, Dodd, & Pantilat, 2008; Lou, Yates, McCarthy, & Wang, 2013; Williams et al., 2010; Yang, Chen, Huang, Pan, & Li, 2010).

Traditional Chinese Medicine (TCM) is used by many Chinese people to help manage symptoms and improve general well-being. TCM focuses on the whole person and considers disease to be caused by the imbalance between the external environment and internal environment of the human body. Adherents to TCM believe it improves immunity by enhancing a person's ability to defend against disease. It works in two ways: when the immune system is depressed, it works to enhance defensive ability. When the immune system is over active, it works to depress defensive ability (Yan, 1999; Yin, 1992). However, we do not know specifically in what ways Chinese tongue cancer survivors use TCM to enhance their recovery and survivorship and this will be important to understand in designing effective intervention strategies (Asher, Seidman, & Snyderman, 2001; Cassileth & Deng, 2004; Chow et al., 2010; Wong, Sagar, & Sagar, 2001).

Of the surgical interventions for tongue cancer, partial glossectomy with flap reconstruction is one of the most common procedures for tongue cancer in China. The prognosis for oral cancer has improved greatly in recent years due to reconstruction with micro vascular free flaps, resulting in broader and safer resections. Survivors now can retain some tongue function, speech function, and experience fewer facial changes. The major goal of this surgical intervention is to remove the cancer. However, despite improvements, this intervention is still associated with considerable long-term effects, lasting well after the immediate recovery from surgery including different levels of voice, speech, deglutition, facial change and other defects, all of which may affect the survivor's quality of life (QoL) (Dziegielewski et al., 2013; Schuster & Stelzle, 2012; Wang, Luo, Liu, Fu, & Zhang, 2013; Yang et al., 2010). Understanding how these sequelae affect and are managed by Chinese tongue cancer survivors is critical for health care providers in order to develop and test interventions to better support cancer survivors' adaptation to and management of the sequelae that most affect their daily lives (Demez & Moreau, 2009).

Health care providers need to understand the physical, psychological and sociological conditions of the patient from their perspective in order to facilitate

new coping strategies. These conditions may facilitate or impede survivors' rehabilitation process and adaptation to treatment-related symptoms (Zarek, 2006). Many of the studies with head and neck cancer survivors cover a heterogeneous population of oral, oropharyngeal, and laryngeal cancer cases. Those that included tongue cancer described a variety of surgical interventions making it difficult to identify particular sequelae associated with a specific intervention and their effect on daily life and QoL (Semple et al., 2008; Zarek, 2006). Evaluating how QoL is affected by specific treatment-related symptoms is important to further our knowledge about the impact of such alterations from the survivor's point of view in order to develop effective symptom management strategies and patient education that meet patients' concerns. Adaptation to post-surgical defects can be facilitated with patient-focused interventions. Although there has been valuable research on head and neck cancer (Semple, Sullivan, Dunwoody, & Kernohan, 2004; Swore Fletcher, Cohen, Schumacher, & Lydiatt, 2012), little focuses on tongue cancer specifically, and still fewer studies focus on the affect of treatment-related symptoms on daily life and QOL, especially for tongue cancer survivors in China. Therefore, the goal of our study was to understand how tongue cancer treatment-related symptoms affect daily life at one year following glossectomy with free flap reconstruction in China.

## Methods

We used a descriptive qualitative study (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005; Semple et al., 2008) design with individuals one year following subtotal glossectomy with free flap reconstruction for tongue cancer at a major Chinese Provincial Tumor Hospital. Our methodology elicits the experiences of individual participants in order to identify broader themes. We used a semi-structured interview guide with 16 participants who had partial glossectomy and free flap reconstruction one year prior to the interview.

### Participants and settings

The study was approved by the hospital research ethics committee prior to recruitment and all participants agreed to participate in the research and gave their oral or written informed consent. The principal Chinese investigator reviewed study procedures with potential participants, provided opportunity to ask questions, and verified understanding of consent. Potential participants were purposively selected from the hospital

data base of medical records to include survivors who had a subtotal glossectomy with free thigh flap reconstruction 11- 14 months prior to the interview. We wanted to sample individuals who had the experience of surviving with the effects of partial glossectomy for one year. We chose one year, because participants would be able to speak about their healing process and their recovery experiences reflexively. The setting was a provincial tumor hospital, and a university medical school's associated hospital which specializes in oncology in an urban setting. Cases were retrieved from the electronic medical record from June 01, 2010 to May 31, 2011. There were a total of 117 subtotal glossectomy with free flap reconstruction for tongue cancer cases (male 107; female 9). The first author contacted potential participants by telephone, explained the study, and invited participation. For those who had time at the contact call, the interview was conducted immediately after receiving verbal consent. For those who did not have time, an appointment was made to conduct the interview at a later time. Approximately 50 people (male 46; female 4) were approached. Of those contacted 15 were ineligible (male 13; female 2), 10 were deceased (male 9; female 1), and 9 refused (male 8, female 1) leaving a total of 16 participants all of whom were male. The inclusion criteria were as follows: 1. orientation to time and place, 2. one year post- partial glossectomy for tongue cancer and free thigh flap reconstruction, 3. current contact information available, and 4. over 18 years of age.

### Data collection

Data were collected using a semi-structured interview guide and from medical records review. One interview was performed with each participant by the first author. All except one participant was interviewed by telephone. One participant who lived near the hospital was interviewed in-person. The senior author, a qualitative expert and collaborator, trained the first author, an experienced nurse with extensive background with head and neck cancer survivors. As an experienced oncology nurse, the first author was sensitive to the need for accommodations in interviewing individuals who have had head and neck surgery and to their special emotional concerns. Interviews lasted from 30 to 40 minutes. All interviews were conducted in Mandarin and audio-recorded. All participants were able to communicate effectively though some participants needed to speak slowly or occasionally repeat.

Participants' sociodemographic information was collected prior to the interview and included age, marital status, education background, and professional status. Interview questions were derived from a review of the literature and clinical experience with tongue cancer survivors. A semi-structured interview guide was piloted to check for appropriateness and understanding. Revisions were made to improve the clarity and flow of the guide. We used broad, open-ended questions. Participants were asked to talk about physical changes, daily life changes, social activities, relationship changes, emotional concerns, use of TCM, and sexual activity. Prompts elicited more depth. Interviews were in Mandarin and transcribed verbatim in Mandarin. Mandarin transcripts underwent a careful translation process by the first author and bilingual staff to produce English transcripts that captured meaning and context for qualitative analysis. We abstracted specific participant information, including clinical diagnosis, intervention, age, gender, and surgery date from the medical records.

Throughout the interview and analysis process, team-debriefing sessions led us to the conclusion that the stories were becoming repetitious, indicating saturation on the emergent categories.

### **Analysis**

The data were analyzed collaboratively by two investigators (the first author and senior author) using content analysis techniques (Graneheim & Lundman, 2004). Using a modified segment-by-segment coding process codes which corresponded to the interview guide domains were developed. The first author and senior author reviewed and discussed each code, cross-referencing the coding in English with the original Chinese transcript for clarification and verification of meaning and interpretation. Cooperatively, codes were developed and then clustered into groups that formed categories describing symptoms, their impact on daily life, and the coping strategies used by participants to adapt to treatment-related changes. Again, we returned to the original Chinese transcripts to verify the emergent categories. We then labeled the categories and identified relationships among categories to describe the process used by these Chinese participants to understand and manage the effects of their surgery. All analyses were conducted jointly by the first author and senior author.

### **Findings**

Participants had a mean age of 47 and a median age of 46. Participants ranged in age from 34-64 years. All participants were married men. All but one reported a good relationship with his spouse before and after surgery. Two men reached the sixth year of education, 9 reached the ninth, 2 reached the twelfth, and 3 earned diplomas. Nine men worked as farmers, 3 as industrial workers, and 4 had professional jobs.

The analysis resulted in the identification of several categories related to sequelae of the surgery and survivors' management of those symptoms. We also found that participants used and benefited from TCM as part of the management process. The alterations about which these participants talked were physical changes, modifying social activities, changes in relationships, alterations in social and emotional life, changes in sexual practices, and use of TCM to manage symptoms and improve general well-being. The participants' ability to adapt to these changes enabled them to normalize their postoperative life.

### **Physical changes**

Although most participants stated that their general condition was good, two of them stated they were worse than a year before. Participants reported experiencing the following physical changes: malfunction of mastication and deglutition; xerostomia, tooth loss or tooth sensitivity; taste change; halitosis; limited tongue mobility; speech impairment; feeling weakness or numbness of the shoulder on the side effected by the surgery with restricted mobility in the effected arm; change in facial appearance, sense of taste, and voice; and difficulty swallowing and chewing. Participants spoke openly about how these physical changes affected their lives. One participant attributed inability to resume work to this lingering shoulder stiffness "I cannot drive because weakness of my affected arm." Regarding facial appearance, another participant said, "even though I have facial change it does not affect my outlook much, I feel ok with it." This participant's statement about physical change not affecting his outlook is illustrative of many of the changes about which participants talked.

Physical changes were very often related to eating problems. For example, one participant said, "[for] my surgery a section of my teeth were pulled out. I have difficulty chewing hard food, but I am able to chew it slowly. I eat food (meat, rice, and so on) with

liquid soup or drinks, I feel all my teeth are sensitive; I did not have this problem before, I have it after surgery. I am sensitive to hot, cold, sour, sweet food.” “My taste has changed a lot; my taste is very bad. I need to add more sugar or salt. By doing so I eat food very well.” One participant complained he leaked air when speaking, “my flap reconstruction side has missing teeth, when I speak I leak air. I feel it difficult to speak compared to before surgery.”

### **Social activities**

Participants linked physical changes to adaptations in their social lives. Cancer and the effects of surgical intervention led many of the participants to stop working. This was a major event in their lives as work represented part of their identity and part of their social environment. For these participants, much of their social life was connected to work. One participant stated, “I feel fidgety sometimes, sometimes not. The reason I feel fidgety is I could work, make money before. Now I only play all day and spend money. I only feel fidgety about this matter. My son doesn’t want me work out of the house; he offered me money to play mahjong. I still believe I have my value.” Another participant said “last year I could drive. Now I can’t.” These participants link their ability to work and travel outside the house to their self-esteem. Changes in their physical abilities causes a change in how they identify.

Almost every participant frequently talked about playing “mahjong” or playing cards which are very important social activities in Chinese culture. Some reported engaging in other social activities such as going fishing or playing sports. These participants reported social activity changes as minor in that they were able, at this point, to engage in satisfying social activities. As one participant said, “I feel embarrassed when I speak but I was going out with friends every day.” Another participant said, “I am an active person; I go out every day with my friends during day time. I don’t feel lonely.” They were continuing their social life.

However, physical changes did cause discomfort in some social settings. Eating limitations were the primary discomfort reported by two of the participants. One participant was reluctant to eat out with friends because of his inability to chew foods related to dental loss. He stated, “I don’t want to eat out with friends due to the possibility of insulting the host by refusing food I cannot eat.” He said his friends reassured him that they would not look down him. Another participant claimed

to have no limitations in social activities, but he said, “I cannot have full entertainment for I cannot drink alcohol and smoke when eating out with friends.” Another participant said, “I feel embarrassed when I speak but I was going out with friends every day.”

One health benefit reported was that all of the smokers had abandoned the habit. Other than the one participant noted above, others did not feel that not smoking impaired their social activities.

### **Stability of Relationships**

Participants received support for recovery from their family members. Most participants felt that their relationship with their wife and others remained normal. Most confirmed that family and others provided strong emotional and social support throughout their recovery despite the physical changes caused by the surgery. Exemplifying this, in response to the interview question, “what kind of support do you get from others?” a man said, “I can fully gain support from others when I need, especially my family supports me very well. I don’t have a negative attitude.”

Participants were asked, “How are your relationships with others?” Only one participant said, “I was unable to remain in good relationships with others when I was experiencing flu.” However, this was not related to his surgery. Another reported, “I had a bad relationship with my wife before and after surgery.” This indicated that the diagnosis and recovery process did not bring this couple closer as others experienced. One man described having an affair with a young woman in order to “forget illness.” These participants did not readily discuss sexual activity. However, two participants reported having no sexual activity at the time of the interviews. One attributed this to age, and to both wife and husband not being in good health, while another worried that sexual activity might hamper his recovery.

### **Emotional changes**

Some participants reported experiencing some sadness and worry at different points in their recovery process. While most reported satisfaction with their recovery and optimism for the future, some of the participants’ narratives revealed some depressive symptoms. This implies that having tongue cancer and treatment-related physical changes effected participants’ emotional well-being. One participant worried that the cancer would spread or recur. Another was concerned

about others looking down on him because of his physical changes. One participant stated, "sometimes I felt irritated when I was thinking my family was not kind to me." Another stated, "I'm easily irritated, and when I am alone, I feel myself still sick. I do not think life is very enjoyable. I cannot drink, talking with somebody is difficult...I was fired when the boss heard I had cancer...I am a useless person. I only bring life load [burden] to my family. I feel anxious and lonely sometimes." Even though two participants indicated, "life is not enjoyable," at present, they expressed that "the future is better." Even though we did not ask specifically about thoughts of the future, participants spontaneously talked about this. We explored this further as it developed into a category.

### Use of Traditional Chinese Medicine

Most participants reported taking TCM to relieve cancer treatment side effects, such as excess saliva, "Huo" (feeling bad in general), or maintaining normal daily life. Participants talked about using TCM to minimize drooling, improve mood, and to help them have better energy - enabling them to return to daily living activities. They felt that TCM was very effective. Participants also felt that TCM would help them remain healthy. For example, one participant said, "I have always felt thirsty after surgery; I have to use 'medlar,' 'ginseng', and 'maidong' [medicinal herbs] together with boiled water. I drink it all the time. I feel better

when I drink it." Another participant said, "I am using TCM to adjust my body function." Another said, "I felt my arm was numb. After I took TCM for a few days, I felt it getting better." TCM was considered an effective way to manage treatment-related symptoms and improve general health by these participants. This indicates TCM is important to patients' perspectives of their recovery process and warrants more research.

We explored interaction between the categories using common constructs in health services research: changes, adaptations, and normalization. We mapped the consequences of physical, social, emotional, and relationship changes post treatment to shared adaptation processes and finally to the team's interpretations. This is illustrated below in Figure 1.

### Interpretations

Results of this study demonstrate that despite major visible facial changes and limitations in eating and speaking, all of which can be important to emotional and social well-being, these participants reported minimal change to their daily activities with the exception being numbness, stiffness, and limited mobility in the shoulder and arm on the surgical side. Significantly, they describe the types of adaptations used to return to their usual activities within the context of Chinese culture.

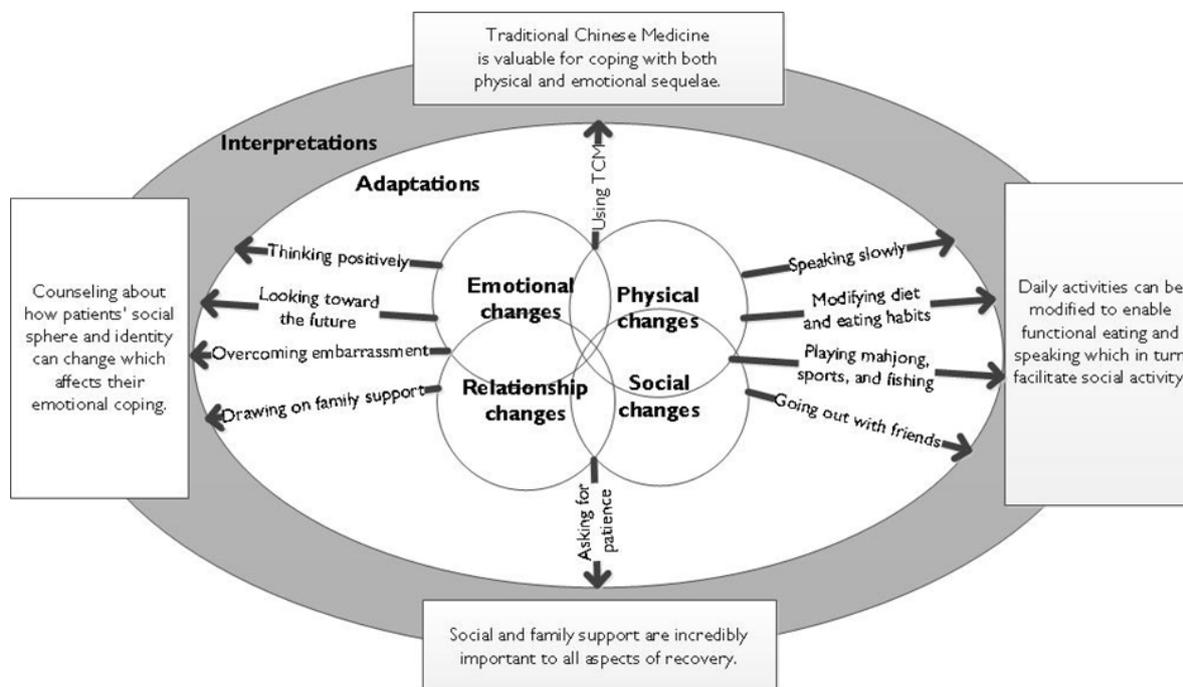


Figure 1. Post surgery changes, the adaptation processes, and the research team's interpretations.

### **Physical changes as Impetus for Adaptation**

Physical changes effected participants' physical or social activities, and required adaptation to create a new normal. Results illuminate that changes experienced by participants included physical changes: mal-function of mastication and deglutition, xerostomia, tooth loss or tooth sensitivity, taste change, halitosis, tongue mobility limitation, speech impairment, and feeling weakness or numbness of the shoulder on the side effected by the surgery with restriction of mobility in effected arm. These findings are consistent with other researchers (Escoda-Francoli, Rodriguez-Rodriguez, Perez-Garcia, Gargallo-Albiol, & Gay-Escoda, 2011; Hahn & Kruskemper, 2007). Participants in our study had difficulty chewing which is consistent with the findings of others. One report reveals surgical intervention has a large negative impact on oral function; reduced masticatory function limits food choice options. An altered food choice may result in lower intakes for key nutrients and weight loss. In our study, participants selected soft foods and ate slowly to adjust to masticatory malfunction. By doing so, they were able to avoid nutrition problems identified in other studies. Participants also often swallowed food with fluids to overcome difficulty swallowing due to xerostomia. Speech impairment was mostly due to loss of teeth and limited tongue mobility. Participants also claimed leaking air through missing teeth when speaking was the main reason their speech was affected. These participants reported learning to speak more slowly and to be patient about repeating. Some participants also experience a change to their sense of taste (Hahn, Kruskemper, Enkling, & Kübler, 2007; Wierzbicka, Kuśnierkiewicz, Wójtowicz, Maune, & Szyfter, 2001) after surgery which effected their eating. An adaptation strategy for this was adding more salt or sweetening to foods.

The major reason for perceived decreased strength was feeling weakness or numbness in the shoulder on the effected side which is due to resection of accessory muscles during surgery causing nerve damage to the area (Lauchlan, McCaul, & McCarron, 2008). This affected some participants' ability to work and was the main reason for not returning to work or having difficulty driving. There is a great deal of Western literature about post operative rehabilitation for eating, speaking, and swallowing, but less attention has been paid to shoulder pain and limited mobility (Goldstein et al., 2014; Kammer & Robbins, 2011; Lauchlan et al., 2008). Recent literature from physiotherapists suggests that a holistic rehabilitation program post surgery, which in-

cludes physiotherapy of the shoulder, can improve not only function, but also quality of life (Lauchlan et al., 2011; McGarvey, Chiarelli, Osmotherly, & Hoffman, 2011; McGarvey, Osmotherly, Hoffman, & Chiarelli, 2013). The extent to which shoulder and arm weakness affected daily activities for participants in this study is a notable finding which could be addressed.

### **Culturally specific aspects of recovery**

Participants indicated that the most important factor in relieving emotional tension and facilitating recovery was the support of family and friends. This support facilitated the physical, emotional, and social recovery process. Studies across many types of cancer have found this (Gore JL et al., 2005; Chan et al., 2004; Furness, Garrud, Faulder, & Swift, 2006; Karnell, Christensen, Rosenthal, Magnuson, & Funk, 2007; Langer, Brown, & Syrjala, 2009; Low et al., 2009; O'Brien, Roe, Low, Deyn, & Rogers, 2012; Semple et al., 2008; Zarek, 2006) and particularly in cultures, such as Chinese culture, in which family is central.

Smoking, drinking, and eating also play an important role in Chinese men's social lives. These men had to overcome embarrassment, ask for patience, and modify their eating and speaking patterns to re-engage in society. Through these adjustments, these Chinese survivors did not experience major disruptions in their eating and socializing (Bell et al., 2009). Throughout the entire recovery process TCM was a valuable complementary resource which alleviated physical and emotional challenges allowing the men to return to socializing.

### **Limitations**

Our study is not representative of all of China. It included participants receiving tongue cancer surgery in one provincial hospital in China. Also, there are limitations in the interpretation of meaning between Mandarin and English even though great care was taken to capture meaning rather than literal translation. Also, all participants were men and women may have a different experience. However, this may be expected because activities such as areca nut and tobacco use that are associated with oral cancer are seen predominantly in men in this area of China. Finally, our study does not shed light on the extent to which the treatment-related symptoms experienced by our participants are present in other settings across China. Despite these limitations, our results provide valuable insights into the recovery and

adaptation process following tongue cancer surgery in China.

### **Implications for Practice and Research**

Support of family and friends was a major factor facilitating recovery from tongue cancer surgery and adaptation to long-term sequelae. TCM can be a complementary source for symptom management. Nursing research internationally could evaluate how TCM is used and valued by cancer patients. There is a growing movement to systematically evaluate the physical and psychological effect of TCM and nurses are well positioned to contribute (Efferth, Li, Konkimalla, & Kaina, 2007; Jin, Ma, Gao, Hua, & Dou, 2014; Li et al., 2013; Liu, Tang, Wang, & Lee, 2011; Williams et al., 2010; Wong et al., 2001). One of the major impediments to resuming normal activity was decreased strength of the affected limb, with weakness or numbness of the shoulder on the affected side due to excision of accessory muscles. This suggests that an area for intervention development and testing might be an early exercise intervention to promote muscle strength and shoulder mobility. Also, collaboration with surgeons may result in investigation of the possibility of sparing some of the accessory muscles.

Based on our findings, further work is needed to develop patient education guidelines for self-management of symptoms related to tongue cancer surgery that are based in the perceptions of survivors' needs. Our results demonstrate that Chinese survivors have the capacity to adapt to permanent physical changes and establish new behaviors which balance their emotional, social, and relationship needs. Our results may also be useful in a pre-operative setting, during patient counseling. They offer more detailed information concerning transient or persistent symptoms and disabilities resulting from the surgery and facilitate improved anticipatory guidance for patients.

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