The decision-making experiences of patients with oral cancer when seeking medical treatment

ABSTRACT

This study was carried out to understand the experiences of patients with oral cancer with the decision to seek medical treatment. This qualitative study conducted in-depth interviews to explore the decision-making experiences pertaining to the medical treatment-seeking behavior of patients with oral cancer. Purposive sampling was used to enroll participants diagnosed with oral cancer who had received at least one treatment (surgery, chemotherapy or radiotherapy). A total of eight (8) patients with oral cancer completed the interviews. The patients with oral cancer enrolled in this study decided to seek medical treatment one to two months after experiencing oral symptoms at the hospital. Content analysis of the interviews revealed five (5) categories: discovering changes but not paying attention to them; managing these changes by themselves; feeling that something is wrong; repeatedly thinking about whether to receive treatment and deciding to take action. When deciding to seek medical treatment, patients with oral cancer reported suspicion towards assessment of symptoms before deciding to seek treatment; this process reflected lack of perception identifying pre-cancerous symptoms, lack of consultation with accurate medical resources and fear of unknown treatment results that led to a delay in medical treatment. Medical professionals should increase the ability of groups at high risk of oral cancer to identify pre-cancerous symptoms, provide them with accurate medical treatment and care and also assist them in adapting to physical and psychological changes to ensure early discovery and treatment.

Key words: Oral cancer, seeking medical treatment, experience.

INTRODUCTION

According to statistics from the International Agency for Research on Cancer, 2015, the number of patients globally with oral cancer was 300, 337 and 198, 975 of them were males (International Agency for Research on Cancer, 2015). The Taiwan Cancer Registry Annual Report (2009) noted that 4, 902 patients were confirmed with a diagnosis of oral cancer. Within the past decades, the growth of the standardized mortality rate was as high as 13.2% with the mortality rate increasing each year as of 2012.

Oral cancer is one of the five most common types of cancer in Taiwan and is one of the major diseases of male patients under the age of sixty (60) (Ministry of Health and Welfare, 2014). Middle-aged people suffer the most from oral cancer, which is the most recently discovered cancer in Taiwan. Its mortality rate in patients aged between 25 to 44 years and even exceeds that of lung cancer and liver cancer. The influence of oral cancer on families and the society cannot be overemphasized (Department of Health Executive, 2011). Due to pre-cancerous symptoms such as oral leukoplakia (OLE), oral submucous fibrosis (OSF), oral lichen planus and verrucous appearance they are usually insignificant.
and not painful and their severity is not directly life-threatening and patients often overlook these initial symptoms (Fisher et al., 2005; Akhtar et al., 2012). The symptoms usually advance to oral cancer within a year of their occurrence (Joshi et al., 2014).

For the reason that pre-cancerous symptoms are often confused with dental symptoms, patients typically seek medical treatment at dental clinics (Scott et al., 2006; Joshi et al., 2014). Studies on this topic revealed that 25 to 50% of patients with oral cancer started seeking for professional medical assistance 1 to 3 months after perceiving abnormal oral symptoms (Jafari et al., 2013; Molassiotis et al., 2010; Tromp et al., 2005).

In Taiwan, 51.8% of patients newly diagnosed of oral cancer suffer from stages 3 and 4 forms, while 44.3% of them suffer from lymph node metastasis in the neck as at when they are newly diagnosed (Huang et al., 1994). In addition, the tumor size of 91.1% of these patients exceeds 2 cm (Huang et al., 2015). The 5-year survival rate for patients with an early stage of oral cancer is as high as 75%, while that of those with advanced stages is only 20%. If patients could recognize abnormal symptoms early and receive proper treatment, the therapeutic complexity and medical costs could be reduced (Lian et al., 2013).

Men represent the primary population of individuals suffering from oral cancer. When faced with symptoms and treatments, male patients are usually unwilling to discuss the issue and tend to observe their symptoms or just wait. Moreover, their expected social and economic roles also affect their medical treatment-seeking attitudes (Galdas et al., 2005; White, 2006). Chemical irritants, such as tobacco, wine and betel nuts are the main causes of oral cancer (International Agency for Research, 1985). Grant et al. (2014) observed that when the disease was caused by chemical irritants, patients tend to perceive negative feelings of being condemned or stigmatized during the medical treatment-seeking process further hindering their treatment-seeking attitudes.

Chang (2009) indicated that individuals will adjust their own behavior toward the disease based on the disease type and severity and their past experience managing the disease, interactions with medical personnel, social cultural evaluation of different medical systems and information exchange with other patients. Chang (1998) analyzed the medical treatment-seeking behavior of the public in Taiwan and showed that mild traditional Chinese medicine; medical insurance, medical suggestions from family or friends and interactions with medical personnel were all main factors affecting a person’s medical treatment-seeking behavior. In relation to medical resources, the referral of non-professionals was found to play a very important role since they primarily provide assistance to seekers with emotional support and information (Chang, 2009).

Grant et al. (2014) investigated the medical resource seeking of patients with cancer and found that their informal medical resources included friends, neighbors, newspapers and magazines, media and the internet. In terms of the medical treatment-seeking behavior of people in Taiwan, 90% of families first addressed the disease on their own and their medical treatment choices were made according to their own foresight or suggestions from other patients. Although the current professional medical system and the medical knowledge available are widespread, the medical treatment-seeking behavior of the Taiwanese public and the decision to exhibit such behavior are still typically affected by non-professional resources.

According to the Taiwan Cancer Registry Annual Report (2012), the number of patients suffering from oral cancer increased to 7,047 from 6,560 in 2010 and oral cancer showed the fastest growth of any cancer in the male middle-aged population. Regarding these patients’ characteristics, most were from the working class and had an educational background of junior high school and under. In addition, more than 80% of them had the habit of chewing betel nuts. When experiencing oral abnormalities, lack of awareness of oral cancer and an inaccurate concept of how to manage it resulted in 51.8% of oral cancer cases being either stage 3 or 4 (Huang et al., 2015). The purpose of this study is to understand the decision-making experiences of patients with oral cancer regarding their medical treatment-seeking behavior.

MATERIALS AND METHODS

Design

This qualitative study conducted in-depth interviews to explore the decision-making experiences pertaining to the medical treatment-seeking behavior of patients with oral cancer. The researcher personally contacted patients with oral cancer to obtain their verbal and written consent and then performed in-depth interviews to collect the data. A semi-structured interview guideline (Table 1) was created after discussions with three PhD-level researchers specialized in qualitative methodology and who studied oral cancer. Before data collection, a pilot study was conducted to confirm the appropriateness of the interview guideline.

Setting and participants

This study used purposive sampling to select patients enrolled at the outpatient clinic and ward of the Division of Otolaryngology in a certain teaching hospital in northern Taiwan. The inclusion criteria were: (1) patients diagnosed with oral cancer (cancer occurring in the lips, buccal mucosa, gums, tongue, bottom of mouth, hard and soft mandible, pharynx, or lower throat); (2) patients with oral cancer who had received any one of the following treatments: surgery, chemotherapy or radiotherapy and (3) conscious patients who could use language to express...
Table 1: Interview guide.

<table>
<thead>
<tr>
<th>S/No.</th>
<th>Interview questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>How did you find your oral cancer?</td>
</tr>
<tr>
<td>2</td>
<td>What decisions did you make when you discovered such changes? What did you take into account when making these decisions?</td>
</tr>
<tr>
<td>3</td>
<td>What situation made you make these decisions?</td>
</tr>
<tr>
<td>4</td>
<td>How long did it take for you to decide to receive professional medical treatment following the changes in symptoms of the mouth?</td>
</tr>
<tr>
<td>5</td>
<td>What situation made you decide to receive professional medical treatment? What impressed you most during the treatment?</td>
</tr>
<tr>
<td>6</td>
<td>During this process, who helped you the most?</td>
</tr>
<tr>
<td>7</td>
<td>If you were offered another chance, what would you do? What would you recommend?</td>
</tr>
</tbody>
</table>

Table 2: Participants’ basic information.

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Education level</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>TNM</th>
<th>Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>41</td>
<td>Elementary school</td>
<td>Female</td>
<td>R’t buccal Ca</td>
<td>T4N0M0</td>
<td>IVa</td>
</tr>
<tr>
<td>2</td>
<td>55</td>
<td>Senior high school</td>
<td>Male</td>
<td>R’t tongue Ca</td>
<td>T1N0M0</td>
<td>III</td>
</tr>
<tr>
<td>3</td>
<td>40</td>
<td>Junior college</td>
<td>Male</td>
<td>L’t tongue Ca</td>
<td>T1N1M1</td>
<td>I</td>
</tr>
<tr>
<td>4</td>
<td>44</td>
<td>Senior high school</td>
<td>Male</td>
<td>R’t tongue Ca</td>
<td>T3N2M0</td>
<td>IVa</td>
</tr>
<tr>
<td>5</td>
<td>55</td>
<td>Senior high school</td>
<td>Male</td>
<td>L’t tongue Ca</td>
<td>T2N2M0</td>
<td>IVa</td>
</tr>
<tr>
<td>6</td>
<td>53</td>
<td>Senior high school</td>
<td>Male</td>
<td>L’t tongue Ca</td>
<td>T4N0M0</td>
<td>IV</td>
</tr>
<tr>
<td>7</td>
<td>59</td>
<td>Elementary school</td>
<td>Male</td>
<td>L’t buccal Ca</td>
<td>T4N0M0</td>
<td>IVa</td>
</tr>
<tr>
<td>8</td>
<td>70</td>
<td>Junior college</td>
<td>Male</td>
<td>R’t tongue Ca</td>
<td>T2N1M0</td>
<td>III</td>
</tr>
</tbody>
</table>

their experiences. The exclusion criteria were: (1) patients who found it difficult to speak after the surgery; (2) patients with mental illness and (3) patients with oral cancer who could not participate in interviews for 30 to 60 min. This study interviewed a total of eight (8) participants (7 men and 1 woman). Six of them suffered from tongue cancer, two suffered from buccal cancer, while 4 of were diagnosed with stage IVa (50%). The age of the participants ranged between 40 to 70 years, while the average age was 52.13 years. The educational background of most of the participants was senior high school level (4 participants). All of the participants stopped working since they had to undergo surgery and dedicate a long period of time to post-operative recovery. The primary caregiver during hospitalizations was mainly the spouse (6 participants) (Table 2).

Data collection and analysis

Before the formal interviews, the researcher followed the inclusion criteria and developed a relationship with the patients and their primary caregivers through an introduction from their attending physicians. Afterwards, the researcher explained the research purpose and process to them informing them that they were entitled to withdraw from the study or terminate the interviews at any time. If the patients were willing to participate in the interviews, the researcher began interviewing them according to the interview guide after they had signed an informed consent form. The researcher interviewed the participants in their respective wards or during non-outpatient clinic hours in a location where no one would interfere. The interview duration was determined according to the participants’ willingness. Each interview lasted 30 to 60 min and was fully recorded. The interview was administered according to the interview themes and the reflections of the participants. The researcher respected the participants’ subjective feelings and did not interrupt any of their thoughts. The researcher also paid attention to the environment of the interviews to avoid content deviation caused by interference. The participants’ names were all replaced by codes in the data to protect the participants’ privacy. The data, recorded data and transcripts of the patients’ interviews were all properly stored.

The first author completed this study’s interviews. After the completion of the interviews, the researcher converted the recorded data into transcripts without any changes, additions or deletions. The experiences described by the participants were authentically and fully recorded. To increase the accuracy of the data analysis, all of the
authors of this study jointly analyzed the data. The number of participants to be enrolled was determined based on data saturation. This study interviewed a total of eight (8) patients with oral cancer. During the analysis of the 7th participant, no new categories were generated, which also occurred during the analysis of the 8th participant. Therefore, the enrollment was terminated after the 8th participant. This study used the content analysis method proposed by Graneheim and (2004) to analyze the data.

To avoid the distortion of data and comply with authenticity, the interviews and data analysis were both performed in Chinese (native language of the participants). The data were then translated into English by professional translators. Afterwards, the transcripts were reviewed by two researchers in English one by one to increase data accuracy.

**Rigor**

This study used the four standards proposed by Lincoln and Guba (1985) to ensure the rigor of the qualitative research data: credibility, conformability, transferability and dependability. Open-ended interviews were used to verify the participants’ responses and participants were asked to validate the findings so as to establish credibility. The first author, who has a doctoral degree was trained for qualitative interviewing and had worked and conducted all of the interviews to maintain consistency of the interview process at an oncology unit. The typed transcripts were carefully reviewed again by listening to each tape to ensure the accuracy of the transcripts. By using a few controlling conditions, variations in the sampling analysis of a large volume of qualitative data helped to establish transferability. Dependability was validated using a peer review analyzing process. Three researchers specialized in cancer care and qualitative studies completed the data analysis of the verbatim text alone and thereafter, cross-examined the analysis.

**Ethical considerations**

This study performed in-depth interviews using semi-structured interview guides. To ensure the rights of participants, the study was approved by the ethical review boards at each hospital. In addition to the written information provided during recruitment, the purpose and process of the study, including the participant’s rights and the protection of their identity were discussed and a signed consent form obtained prior to the interview. During the interview, if a participant raised a sensitive issue or provided sensitive information, support was provided and the maintenance of confidentiality reassured. In addition to protect the identity of the participants, the researchers used letters (A to H) instead of the participants’ real names to present the documents or reports of this study.

**RESULTS**

This study found that the decision-making experience regarding the medical treatment-seeking behavior of patients with oral cancer covered five categories: discovering changes but not paying attention to them; managing the changes by themselves; feeling that something is wrong; repeatedly thinking about whether to receive treatment; and deciding to take action. There was a certain order and context to their medical treatment-seeking experiences (Figure 1).

**Discovering changes but not paying attention to them**

The participants indicated that at the initial stage of occurrence of cancer, they experienced damaged mucosa and oral pain. However, they believed that these discomforts were experienced by everyone in their daily life. The oral discomforts such as when eating and not paying attention to them affected their daily life. Some factors considered were:

- *Experienced by everyone*: The participants viewed their symptoms, such as oral pain as experiences that everyone had.
- *Affecting their life, but with no attention paid*: Although the oral discomforts affected their life, the participants paid them no attention. For example:

  ‘My mouth hurt so much that I could not eat porridge. It hurts even more when I ate hard food. It also hurts a lot when I slept. However, these discomforts were tolerable but I tolerated them not paying attention to them’ (Participant C).

**Managing the changes by themselves**

When the participants experienced oral changes and symptoms of discomfort, they managed them according to their past life experiences and other people’s suggestions and by seeking general medical treatment. The descriptions given are:

- *Handling changes according to past experiences*: The participants treated oral changes, such as damaged oral mucosa, pain and bleeding according to their past experiences or from suggestions of friends. For example, they took or applied Chinese and western medicines and used saline or alcohol to rinse their mouth. For instance:

  ‘Many people experienced oral pain when chewing betel nuts. We would rinse our mouth with saline or directly
place salt in our mouths. Although it hurts, the salt could be used for disinfection. We would use rice and sorghum wines to rinse our mouths for disinfection. Many betel nut chewers use wine for disinfection’ (Participant G).

- **Purchasing over-the-counter (OTC) drugs:** After experiencing oral discomfort, the participants purchased OTC drugs at a pharmacy on their own (for example, Chinese herbal powder and anti-inflammatory drugs) to use as treatment.

- **Seeking general medical treatment:** After the oral pain and inflammation repeatedly occurred, the patients started to visit general clinics to seek treatment for their symptoms. For example, one participant said:

> ‘My damaged oral mucosa never healed, so I decided to go to a clinic. Afterwards, I went to a clinic near my house to take the drugs for treatment. Because the drugs were ineffective, I went to another clinic. The physician at the clinic told me that it might be mucosal inflammation. Because it did not hurt, I prescribed drugs and mouthwash’ (Participant F).

**Feeling that something is wrong**

After failures in self-management and the medical treatment of symptoms, such as damaged oral mucosa, pain and bleeding, the participants began to think that there might be something wrong with their oral cavity. At the same time, they told themselves that these symptoms were not life-threatening and should not be too severe. For example, one participant said that:

> ‘I thought that the symptom that appeared in my uncle's oral cancer was reddish oral mucosa. My oral mucosa was white, so I ignored it and thought that it was not that severe and as such would disappear’ (Participant H).

Although the participants told themselves that their oral problems should not be too severe, they became suspicious regarding their non-healing damaged oral mucosa, lasting pain and aggravated pain. For example:

> ‘About half a month ago, I started feeling odd about my throat and the situation never improved. There was indeed something wrong. My throat hurts and I even felt uncomfortable when swallowing saliva for more than a month. I started to feel something was indeed wrong’ (Participant C).

**Repeatedly thinking about whether to receive treatment**

Although the participants recognized the severity of the delayed healing of their oral symptoms and the uncontrollable bleeding and pain, they also worried about the substantial impact that unknown treatments would have on their current lifestyle, work, economy and family. Therefore, they experienced the contradiction of deliberating over whether to visit the hospital. Some factors considered were:

- **Worrying about the influence of treatment on physical function:** The participants indicated that because they worried about the adverse effects of uncertain treatment processes on their physical functioning, such as speaking, eating, or singing, they hesitated about going to a hospital. For example:

> ‘I thought about surgery and was afraid that the surgery would involve having my tongue removed, so that I would not be able to speak, sing and eat. When I thought about it, I was worried about and afraid of visiting the hospital. It was possible that if I had to undergo a tracheostomy, my life would be ruined’ (Participant B).

- **Worrying about the influence of treatment on life:** The participants indicated that they worried about the influence of treatment on their current work and family lifestyle as well as being a burden to their family economy. Therefore, they hesitated over whether to visit the hospital.

**Deciding to take action**

After the participants hesitated about going to the hospital for a period of time, medical professionals informed them about the severity of their symptoms, such as delayed healing of damaged oral mucosa, uncontrollable bleeding and pain and that there was a possibility of oral cancer. They realized the severity of their symptoms, felt that they should not delay any further and decided to go to the hospital to receive medical treatment. Some factors considered were:

- **Perceiving the severity:** After experiencing the symptoms, such as delayed healing of oral mucosa, repeated bleeding and pain, as well as the failures of self-management or treatment at general clinics, the participants began going to different clinics to seek assistance. When the medical personnel informed them of the possibility of oral cancer, they realized the severity of their symptoms and felt that they should not delay treatment any longer. For example:

> ‘The ENT specialist was shocked on seeing my tongue. I knew that it was severe and that I should no longer delay the treatment’ (Participant C).

- **Receiving treatment:** The participants indicated that after the medical professionals had informed them of the
DISCUSSION

The study results showed that before receiving a confirmed diagnosis of oral cancer, patients with oral cancer experienced abnormal changes in their oral cavity with symptoms such as oral leukoplakia, ulcers, pain, and tumors - all components of pre-cancerous lesions of oral cancer (Akhtar et al., 2012; Gao and Guo, 2009). They decided to go to the hospital after living with these symptoms or treating themselves for approximately 1 to 2 months. This finding is consistent with that of other studies. It takes an average of 1 to 6 months for patients with oral cancer to visit the hospital after experiencing oral changes (Esmaelbeigi et al., 2014; Joshi et al., 2014; Tromp et al., 2005; Scott et al., 2006). If these pre-cancerous symptoms are not treated on time, 13 to 19.3% of them will advance to oral cancer (Forrest et al., 2014).

Since the oral symptoms of patients with oral cancer are usually not painful in the early stages and because such changes do not have a severe influence on their daily life, patients may easily overlook the severity of these problems. Laronde et al. (2014) in their study indicated that before deciding whether to go to the hospital, the main considerations of patients were whether the symptoms would disappear or continue to progress. Most of the patients paid no attention to the oral changes or symptoms, but after undergoing self-treatment and general medical treatment, they started to become aware of the severity of the problems after some time. As a result, the severity and complexity of the disease increased by the time they received medical treatment (Grant et al., 2014; Joshi et al., 2014). This finding is consistent with that of a study suggesting that patients’ lack of knowledge or early judgment of oral cancer symptoms (Jafari et al., 2013) further led to delayed medical treatment-seeking behavior.

In this study, 90% of the participants were males and their average age was 52.13 years. When facing an important life event and the choice of treatment, the participants still worried about the influence of treatment on their work, financial capacity and family and even delayed their medical treatment. This result is consistent with Smith and Popeand (2005), who suggested that the main consideration of male patients when they decide to go to the hospital is whether their daily work will be affected. Moreover, most male patients exhibit the tendency to wait or observe when facing medical treatment. The development and change in symptoms further affects their decision to receive medical treatment (Grant et al., 2014).

When the patients in this study faced abnormal changes, they did not pay attention to them because the symptoms in the beginning were insignificant. When patients’ family members were aware of the patients’ symptoms, such as throat pain, although they would remind the patients about the negative side effects of oral stimulation caused by tobacco and wine and would try to dissuade them from using tobacco and wine, they did not directly recommend them to visit the hospital. Smith et al. (2005) suggested that family or friends of patients usually do not associate symptoms with a disease until the patients’ physical strength has weakened or physical changes have affected their life.

In terms of seeking an improvement in symptoms, patients and family members usually seek assistance from non-medical systems, such as purchasing OTC drugs at a pharmacy (anti-inflammatory gel or watermelon cream) or using folk remedies (salt or rice wine) as a form of symptom relief. This finding is consistent with Joshi et al. (2014) who reported that medical treatment-related information is mainly provided by a professional healthcare system and that patients usually seek assistance from a non-medical system before they obtain accurate information. Joshi et al. (2014) also indicated that when experiencing symptoms in the early stages, 30% of patients with cancer usually propose reasonable explanations of their symptoms to rationalize the changes or will self-medicate to relieve the symptoms and discomfort.

Tod et al. (2008) presented research results showing that family members play a very important role in a patient’s medical treatment-seeking process because the information provided by them affects patients’ choices to seek medical treatment. During the medical treatment-seeking process, in addition to the perception and assessment of symptoms by family members or friends, an individual’s perception of their disease symptoms also occurs. Most participants in this study had oral cancer in stage IVa (47.1%) when they sought medical treatment. For example, participants A, B and G lacked the knowledge to assess their symptoms and perceive disease. Therefore, it took them approximately 6 months to decide to visit the hospital after they had perceived abnormal oral changes. Because this high-risk group showed deficiencies in their perception of oral cancer and ability to judge symptoms, their stage of oral cancer (III to IVa) was more severe than that of other patients. Participants of this study also delayed treatment since they worried about post-operative changes to their physical and social functioning. This finding is consistent with Väisänen et al. (2014) in their study showed that patients who feared medical treatments prolonged medical-care-seeking when having symptoms indicative of cancer. Therefore, medical and nursing professionals should help this group at high risk of oral cancer notice of earlier pre-cancerous symptoms and provide them with medical treatment-related information to reduce the time needed for them to decide to receive medical treatment.
Conclusions

This study performed qualitative interviews with eight (8) patients and a confirmed diagnosis of oral cancer who received at least one medical treatment. The results showed that patients with oral cancer underwent five subjective experiences when deciding to receive medical treatment: discovering changes, but not paying attention to them; handling such changes by themselves; feeling that there is something wrong; repeatedly thinking about whether to receive treatment; and deciding to take action. The results demonstrated that the decision-making abilities of patients with oral cancer in terms of their self-interpretation and self-management of symptoms and their medical treatment-seeking behavior during the disease process should be strengthened.

In the research results, the participants recalled the decision process they experienced regarding their medical treatment-seeking behavior. Thus, the accuracy of the data from the interview content might have been affected by time. Moreover, due to the regional limitation of interviews being conducted at a single teaching hospital, this study could only analyze interview data from one region to obtain research results. Therefore, future studies should interview patients in different regions to increase the depth of the research content.

ACKNOWLEDGMENTS

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REFERENCES

Taiwan Cancer Registry. The Age-Adjusted Incidence Rate and the Long-Term Trend of Oral and Pharyngeal Cancer in Taiwan (2015).

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