

Oral Cancer Patients' Perspectives to Quality of Life: A Qualitative Study in the Context of Northern Thailand Medical and Cultural Systems

Thatsanee Saladyanant¹, Imjai Chitapanarux², Swe Swe Win³, Piyanart Chatiket⁴

¹Graduate student, Division of Community Dentistry, Faculty of Dentistry, Chiang Mai University, Thailand

²Department of Radiology, Faculty of Medicine, Chiang Mai University, Thailand

³Department of Oral Medicine, University of Dental Medicine, Yangon, Myanmar

⁴Department of Family and Community Dentistry, Faculty of Dentistry, Chiang Mai University, Thailand

Received: April 9, 2021 • Revised: May 18, 2021 • Accepted: May 31, 2021

Corresponding Author: **Assistant Professor Dr. Piyanart Chatiket**, Department of Family and Community Dentistry, Faculty of Dentistry, Chiang Mai University, Chiang Mai 50200, Thailand. (E-mail: pichatiket@gmail.com)

Abstract

Objective: To determine oral cancer patients' perspective on quality of life and to explore how medical systems work in the context of cultural systems in northern Thailand.

Methods: A phenomenological study was conducted to make an understanding on oral cancer patient experiences and their perceptions on quality of life. Twelve oral cancer patients were recruited for in-depth, semi-structured interviews. The diverse experiences from patients who have been diagnosed with oral cancer from 2 months to 11 years were collected and the narratives were extracted, categorized, and analyzed into significance themes by using content analysis.

Results: Four themes emerged from the interviews including: (1) ability to cope with cancer under the supportive cultural medicine, (2) family support and social network, (3) accessibility and availability of medical care, and (4) acceptance of new identity. Patients' health believes and values were attached firmly to cultural explanation of disease and expressed through health seeking behaviors. Biomedicine together with cultural medicine both played roles for oral cancer healing, as culture defined meaning of oral cancer and identified healing, thus, patients used pluralistic medicine to cure diseases and heal their illness.

Conclusions: The stigma of cancer is the unprepared-suffering caused by unclear factors. Patients believed karma and curses were causes of cancer. Oral cancer patients need both biomedicine and cultural medicine to heal their organs, emotion, mind, and soul. Supports from social network, government health policy, and socio-cultural constructs help patients to perceive a good quality of life.

Keywords: cultural medicine, medical systems, oral cancer, pluralistic medicine, quality of life

Introduction

Health beliefs and values are attached to social construction and framed by culture; therefore, culture shapes medical perspectives on meaning of illness, treatment protocols, healing processes, and meaning of being healed. Medical systems are part of cultural systems that provide the symbolic meaning of illness and behavior norm in human society. The medical reality of each society is different from others, so we could see the diverse medical sectors playing their roles at the same timing for the different aspects of healing.⁽¹⁻³⁾ Based on Arthur Kleinman study, health care systems contain three sectors: professional, popular, and folk sectors. Professional domain consists of professional in scientific medicine and traditional healers (e.g. Chinese traditional medicine, Thai traditional medicine, Ayurvedic). Popular domain comprises family, social network, and community activities on health and illness management. The last sector, folk domain involves non-professional healers (e.g. indigenous healers, sacred, sorcerers, religious practitioners, Buddhist monks). Together all sectors are constructed and form the identical medical reality of each society.^(1,2)

Unlike other cancers, oral cancer is a deadly disease that appears in the oral cavity destroying facial organs. Cancer itself and medical operations leave severe distortion on patients' face, which makes them feel loss of their social identity.⁽⁴⁻⁸⁾ Oral cancer is scary because of its low survival chances and the fear of painful operations around faces and oral cavities, which are the front-line organs for eating, talking, and feeling expression.⁽⁹⁻¹¹⁾ To bring survivors back to society, treatment regimens for oral cancer needs to contain both biomedical procedures to cure diseases, and cultural medicine to heal patients' mind and soul.^(12,13) Surviving is not the final target of oral cancer treatment, but good quality of life for survivors should be the greatest concern among medical staffs and patient relatives.^(5,10,14-16) The World Health Organization defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".⁽¹⁷⁾ Thus, oral cancer patients' quality of life is their own perspectives on their social world based on their health experiences, health belief, and social structures, as such cannot be necessarily compared to others.

The situation of oral cancer in Thailand is poor. Oral cancer is the sixth most common cancer in Thailand with the incidence rate of 5.5 cases and 4.3 cases in 100,000 populations of Thai male and female, consecutively.^(18,19) A study in northern Thailand found that oral cancer had only 28.7% five-years survival rate with short surviving duration of 1.16 ± 0.7 years. The study showed that patients who were in the 40 years and older group had lower survival rate compared to younger patients (27.4% and 56.2%, consecutively).⁽²⁰⁾ Other studies confirmed the importance of early detection of oral cancer, in which patients with the early-stage of cancer had a higher survival rates compared to late-stage (54.6% and 16%, consecutively).⁽²¹⁾ Nevertheless, both early- and late-stage cancer patients both encountered the toughest time of life and had to deal with every struggle to survive. Support from families, friends, neighbors, community members, social networks, and social welfare are the most important factor that help patients coping throughout their tragedy.⁽²²⁻²⁶⁾ Oral cancer invades patients' life in many dimensions. Cancer itself and the therapeutic procedures harm facial and oral organs, destroy patients' mind and emotion, distract patients from their society, and lock their soul in the fearfulness.^(10,14,27) Biomedical and cultural medicine together have functions to help patients and families get their lives back, or at least, to live with cancer peacefully. In this study, a qualitative approach was used to explore how do medical systems work in the context of cultural systems in oral cancer event and to determine oral cancer patients' perspectives on quality of life and how factors related to quality of life play their roles in oral cancer healing.

Materials and Methods

Study design

The phenomenological study was used to determine patients' perspectives on quality of life⁽²⁸⁾ and the roles of medical and cultural systems in oral cancer healing. Qualitative approach, semi-structured, in-depth interviews were used to collect data from a group of oral cancer patients in Sanpatong district, northern Thailand, with various stages of cancer. Narratives from the interviews were transcribed and coded by their means and were analyzed by using content analysis.

Recruitment

We received a list of oral cancer patients from northern branch center of the National Cancer Registry, the record of Thailand national database for all cancers. We recruited oral cancer patients registered during January 2018 to December 2019 who were (1) diagnosed with oral malignancy tumor, and (2) ≥ 40 years old, and (3) live in Sanpatong district, Chiang Mai province, Thailand. Patients were excluded from the study if they had (1) cognitive impairment, or were (2) too weak to participate, or (3) refuse to participate.

Interviews

The research protocols and interview questions were approved by the Research Ethical Committee of Faculty of Dentistry, Chiang Mai University. (Certificate of ethical clearance No.76/2019). Study duration was approximately 8 months from December 2019 to July 2020. Researchers met with patients prior to the interview day to introduce the project and make the acquaintance with patients. On the interview day, participants were fully informed about the study and gave the consents prior to the interviews. The field note and audio records of all interviews were records for verbatim transcription and data analysis. All conversations, facial expressions, actions, verbal tone, and details of surrounding environment were noted to ensure the dependability. All interviews took place at patients' homes where members of all families were pleased to join the conversations. All participants felt that sickness from cancer spread throughout the entire family. To fight with cancer was the families' business not the individual's fight alone. Their memories on cancer experiences were clear as if it just happened yesterday, even though it might have previously spanned over 5 years for some families. We started conversations with general questions about (1) patient's health belief, life history, religious and social participation, general illness management in family and community, e.g. "how do people in your village normally practice when getting life threatening sickness and why?" or "how do you or your wife/husband do when you/she/he get serious illness?". Then we moved to more specific questions about oral cancer to determine (2) patient's explanation on oral cancer and how to heal their illness, e.g. "what is oral cancer and why do you have it?" "how did you know you have oral cancer?" "how did you fight the cancer?" "how

do you know you were healed?", (3) patient's body, mind, and social changes and how they cope with those changes, e.g. "what were the symptoms and how to cure?" "how did you cope with the suffering?" "what/who help you to cope with the situation and how?" "Types of treatment used to heal your sickness, how and why did you use them?" (4) patient's perception on their quality of life and factors related to quality of life, e.g. "how do you explain your quality of life?" "how does oral cancer mean to your life?" "what are the factors related to your quality of life and how?". The average length of interviews was 45 minutes (range: 30-120 minutes). We used triangulation technique to confirm the consistency of data by asking the similar questions to patients' family members, caregivers, and their neighbors. Results were anonymous and participant numbers were used in the report. After twelve participants were interviewed, the dialogues were repetitive and data we received was saturated enough to represent oral cancer patients' experiences and perspectives. Consequently, researchers decided to stop data collection and used information from those twelve participants for content analysis.

Data analysis

Immediately after each interview, the audio tape records were transcribed and the fieldnotes were reviewed for initial narratives. The narratives were checked by two researchers and two oncology experts before the uncleared issues were discussed again with patients until the researchers were confident that all collected data represented the patients' intentions. Content analysis was analyzed based on Colaizzi's phenomenological analysis method⁽²⁹⁾. Significance statements were isolated from the narratives and meaning from each statement were extracted and categorized into themes of phenomenon. Themes were interpreted under the concepts of this study. After data analysis, we went back to fieldnotes and transcript from audio record to confirm data consistency. The rigor of emerged themes was verified by assessing their transferability, credibility, dependability, and confirmability⁽³⁰⁾.

Results

Participant characteristics and their perceptions on oral cancer

Twelve participants with oral cancer at varying

stages were interviews. The characteristics of cancer, diagnosis, sites, treatments, stages, cancer duration, and patient' details were shown in Table 1. The average ages of participants were 65 years (54-88 years). Caregivers were their spouses or relatives who were in about the same ages as patients, and/or their child. All participants were diagnosed with squamous cell carcinoma, an aggressive type of oral mucosal cancer. Duration from cancer diagnosis or the length of time since diagnosis varied between 2 months to 11 years. Even though the carcinoma was evident at different stages in each patient, similar healing pattern was shown here. All participants were born, grown up, and spent most of their lives in same socio-environment. They are local villagers whose previous careers before getting sick were labors or farmers, except one monk. Two male participants left their families to get jobs in other areas but had returned to Sanpatong since being diagnosed with cancer. Sanpatong is an agricultural and suburb district not far from Chiang Mai City. People stay in extended families where 3 to 4 generations live in the same accommodation. The witch doctors and folk remedies are strongly believed among elderly people while religious-related rituals interpolate as a part of villager's everyday life. The limitation of this study was the survival time of oral cancer patients. About 75% of patients from the Cancer Registries' list died before we contacted them or were too weak to participate. Eventually, we interviewed seven survivors who had already finished their medical treatments with good prognosis, one patient with recurrence stage of cancer, two patients whose treatments were completed with fair prognosis, and two patients in palliative stage with poor prognosis.

All participants agreed that karma, fate, and spirit were reasons of oral cancer since there was no solid scientific explanation to point out the exact sources of cancer. Karma is the Buddhist belief as the reasons for why things happening to current life of living creatures while also being the results of actions in the previous life or previous actions that decide destiny and fate of human. As the 67-years-old male patient (No.4) stated: *“Previously, I loved to do fishing. When fish sucked, hooks stuck and torn fish's mouth. I believed they cursed me for their torture, then I had oral cancer. Since I left hospital for my oral surgery, I had never been back to fishing anymore. Once my neighbor hit pig's head to kill it then he ended up death by train crashing directly at his head. I strongly*

believed karma and curses caused cancer”.

According to the interviews with patients and their neighbors, any risk factors such as smoking, alcohol, genetics, or microbial infection were the accelerators of karma that switched on cancer in their bodies. If they did not have bad fate, they would not get cancer no matter how bad their behavior. Two female patients said that they stopped smoking for more than 30 years, while their neighbors keep smoking but had no cancer. Therefore, karma seems to be the only acceptable reasons for oral cancer in their cases. A 77-year-old female patient (No.2) expressed her feeling: *“I quitted smoking for more than 30 years. I don't understand why I still have cancer. When I was young and worked in the rice field, everyone there smoked to drive insects away. As far as I know, only me have oral cancer”.* While another 69-year-old female (No.3) doubted: *“I have never smoke in my life. Why do I have cancer? I was shocked when I know that I had cancer because I always take care of my health. I was informed that smoking is the cause of oral cancer. I saw my neighbor smokes heavily every day, but he does not have cancer, why?”*

Furthermore, all participants thought that there was no way to escape from their own fate, but they could relieve the fate by using all medical and spiritual tools that they had. We found that participants in this study had positive coping characteristics. They were able to respond to cancer rather quickly by leaving their “diseases” in doctors' hands and faced the “illness” with support from families, neighbors, and spiritual related-community culture. Data analysis to examine patients' perspective on quality of life showed four themes emerged including (1) ability to cope with cancer under the supportive cultural medicine, (2) family support and social network, (3) accessibility and availability of medical care, and (4) acceptance of new identity.

Theme 1: Ability to cope with cancer under the supportive cultural medicine

Cancer is a fearful and life-threatening disease that biomedical treatments alone cannot restore all quality of life. According to the interviews, cancer beliefs were attached to cultural explanation, therefore, cultural medicine had to take part to enforce psychological and spiritual illness elimination. Oral cancer patients had to fight with burdens from both the cancer itself and the social stigma.

As all participants mentioned, the fight with cancer seems to be impossible since it was not a fight with a disease, but their fate. A one 55-year-old female (No.11) survivor said: *“When I knew that I had cancer, I cried a lot and my whole family cried too, why me?...we don't know what to do at the beginning, but everything gets better by now”*. Cancer destroyed oral organs and caused eating, swallowing and speech related problems while surgery left distortions and scars on their faces, destroying their self-images and identities. All participants said they had to face fear of dying, living with suffering, becoming suddenly dependent, and most of all, worrying about their beloved families. A 64-year-old male participant (No.6) stated: *“I had to go through all painful process. The surgery made me feel like I was death and recovered again. I could not eat through my mouth, I had to eat from feeding tube. It was tasteless. I felt hungry even when my stomach was full. The radiotherapy made my throat dry as sand and the chemotherapy made me vomit all day long”*.

Beside the biomedical treatments, local cultural medicine played a psychological and spiritual role in healing. Based on patients' explanations, there were cancer organisms that could appear everywhere. These organisms may intrude into human bodies by eating contaminated food, breathing bad fumes, transferring from parents, or even invading through skin. Somehow, cancer organisms stay silent until karma or curses turn it on. Therefore, cancer patients seek help from cultural medicine such as witch doctors, sorcerers, local remedies, religious activities, making merit, meditation, rituals etc. in order to reduce the force from karma and curses while protecting them from any other bad fates. Participants performed various practices under cultural beliefs such as making merit with Buddhist monks and temples, giving away alms, praying for themselves, making merit for wandering spirits, meditating to get calm, letting witch doctors put a spell on them or letting an indigenous doctor scratch the lump with mantra tools to remove tumor's root. For all participants, the healing process composed of both physical and spiritual combinations. As a story of a 69-year-old female participant with previous alveolar ridge cancer (No.3) stated: *“Since I finish my cancer surgery and other treatments from hospital, I came back to my home and go to stay at temple every Buddhist holy day. My big sister always goes there then she invited me to come with her. At the temple, a lot of people gather to stay*

overnight. We pray 5 times a day, good mantra will protect us from bad spirits. This helps me to get calm, less depress. I feel better and I wish other patients to do so”. Another female participant (No.6) told us about how a witch doctor helped to relieve her from cancer: *“I went to witch doctor to ask for reasons of my cancer. She told me about the enemies from the former life trying to take my life away. Thus, I have to make merit for them to stop the malice”*. Two female participants went to healer because they believed in the power of mantra as one of them (No.9) stated: *“After I was done with modern medicine, I went to healer to make sure that whole cancer had completely gone from my body. Healer had mantra. He spelled, scratched, and blew holy water around cancer area to clear out the left-over evil matter inside.”* A patient's husband told us more about indigenous doctor *“In northern area, the elderly mention cancer as a kind of “evil matter” that occur inside human body and grow outward to skin. Healers would find this matter and destroy it with tiger's fang and mantra. Nowadays, there are very small number of true healers who have pure mantra to cure cancer”*.

In northern Thailand, the “life elongation ritual” led by indigenous doctors and monks is one of the rituals generally practiced whenever anyone in the house got weak or ill. It is the ritual that gathers large groups of people together to prepare for the ritual's day. It has a lot of details, so it needs a workforce to finish the preparation. Thereby, people in the village normally come to assist. Families of patients always announce the ritual before-handed to let the close friends, relatives who have move to another town, neighbors, and people in community gather to join the day. The power of ritual is believed to elongate participants' life and give merit to protect them from bad fate. The ritual gives great encouragement and assigns a good start for patients to return to society. A 67-year-old participant (No.4) who survived from cancer at lateral of tongue shared his experiences: *“Once I was back from hospital, my family prepared ritual for me. People around came to join. They helped to prepare the ritual, food, and stuffs to give for alms. It required a lot of help to make it done. We had to decorate the holy trees delicately with lots of detail on it. On that day I met lots of people after I admitted lonely in hospital for about a month. Relatives and friends came all the way down to my home. We talked a lot about my sickness and treatments. Monks pray mantra to protect me and everyone in the ritual*

from bad fate". In this study, nine families performed the rituals while other three families were too poor to manage the ritual costs. However, monks were invited to their houses and prayed for them instead. The religious explanation about karma also eased patients and families from struggling in the fear of death. Almost all participants thought that being sick and getting cancer were human destiny and may happen to anyone.

Theme 2: Family support and social network

A tied relationship of people in community networks was very important for good coping. Patients' social network included many people such as their families, relatives, friends, neighbors, health professional in local and central hospitals, and other cancer patients whom they met while receiving treatment in hospital.

All participants needed lots of supports from people around them. At the early stage of cancer treatment, patients had to cope with their fear of death, fear of pain, depression, anxiety, and poor emotional responses. During treatment, they had to cope with the side effects of the operations such as suffering pain, facial deformity, nausea, anorexia, xerostomia, dysphagia, and fatigue. Even after surviving, they still had to adjust to their new identity, new way to eat, their strange voice, new lifestyles and most of all, to the fear of cancer recurrence. Therefore, they needed both physical and psychological-emotional supports from their loved ones. Families were the most important supports for all participants. All participants agreed that love and care from families were the most importance factors to solve all the problems and encouraged them to confront the coming burdens. It was not a lonely journey for patients because their whole families had fought with them. As one participant (No.10) with cancer at lateral of her tongue shared in conversation: *"Love and encouragement from family is the best support. If you have good encouragement, you will be fine anyway"*. Another 55-year-old female participants (No.11) also stated: *"There were lots of people came to visit while I was admitted in hospital. My husband and my children slept in the same room to take care of me. My little niece cheered me up all the time. My far away relatives came to visit me from other town every day, I had never felt lonely and was relieved from fear"*. Good wishes from neighbors were another good supporter for patients as shown in a male participant (No.6) conversation: *"My neighbors gave*

me some good food that help me recovered from surgery. They came one by one and gave me almost a thousand of eggs. People all around come to knock on my door to show me their care and love. I feel grateful for their good willingness. I would like them to see me getting better as they wish, so I have to try my best to be stronger".

The understanding from patients' families was very important. Patients had to change from normal food to soft or liquid food. Rice, egg, vegetable, fish, meat, or other sources of protein were all blended for each meal and they had to separate their meals from other family members. One male participant (No.6) who had lost all teeth and mandible from mandibulectomy, ate through feeding tube told us about his appetite for sweet: *"My wife cooks for me. She blended rice, egg, vegetable, pumpkin, and milk together. Although I fed myself through feeding tube directly to my stomach, I still need sweet after meal. I feel not full if I do not have sweet at the end of my meal"*.

Participants' new networks were other cancer patients and health care professional that they had met during the medical treatments. All participants shared the same feeling when they were in hospital. Comparing themselves with more severe cancer patients helped them understand that they were better off than others. A 66-year-old female participants (No.10) remind herself that she was better than the younger patients: *"I saw lots of cancer patients whenever I go to hospital. It is not only me who have cancer. The waiting room in cancer clinic is always crowded with patients. Some of them are very young and some look much worse than me. Compared to myself, I feel that mine is better"*. A special-bond occur at the waiting area as a 77-year-old female participant (No.2) stated: *"Cancer patients came from everywhere, we talked and shared our experiences. We talked about treatments, made friends and shared some health advice. We cheered up and prayed for others. Being among other cancer patients make me felt like normal"*. Cancer patients also shared health information with each other. In participants' opinions, information from their doctors were more reliable but hard to understood, while information from friends or other cancer patients was easier to follow and more practicable. As seen from a female participant (No.2) who had survived from alveolar ridge cancer: *"My neighbors had cancer before me. He survived and gave me an advice which make me felt hopeful. He shared me his cannabis oil. It reduced pain and made me sleep better*

until I got my surgery. Now I'm survived, I have good life, and I'm ready to share my experiences to help others". Good relationships with families, friends, doctors, nurses, strong community network, and the feeling of belonging could help oral cancer patients to have a better quality of life.

Theme 3: Accessibility and availability of medical care

The capability of having access and being cared by cancer experts in central hospital made patients felt safe and gain confidence. All participants said they respect doctors and nurses. Without any doubt, they allowed doctors to choose treatment plans and trusted that doctors would make the best choice for them. They also trusted in power of modern medical technology as one male participant (No.8) who had cancer at the floor of mouth stated: *"When doctor told me about my cancer, I did not feel burden that much. I knew that people normally get shocked if they have cancer, but not me. In my opinion, cancer today is not the same as the old day because doctors know more about cancer. Cancer could happen to anyone and it is our destiny to have it. Everyone has their own destiny".* Almost all participants, except two males who took palliative care, said that they felt better after meeting with doctors and discussing with medical staffs their plans, as one female with cancer at lateral of tongue (No.10) said: *"Doctors are great. Nowadays, they know more about cancer and treatments. Medical technology is more advanced than before. If doctors say yes, it means they really can treat it. I always trust my doctor".* Even after the surgery, which was the worst part of operation, their trust in their doctors made them felt strong as one of male participant with cancer at base of tongue (No.12) stated: *"When I recovered from surgery, I saw lots of tubes hold from my body connected to several machines around me. Whoever saw me said I might not be able to survive, but I do survive! I know that I will survive".*

In Thailand, government provides universal coverage for medical treatment. The universal coverage covers all basic and high-cost treatments to protect people from economic failure via medical treatment. The coverage also includes cancer treatment in public hospitals and medical schools, where cancer treatments are available. Although government pays for the medical charges, patients still had to pay for the extra equipment such as feeding tubes and radiation protective masks. All participants knew that

the actual cost of cancer treatment was very expensive. If there was no coverage from the government, some patients may not have been able to afford treatment, which might have led to them giving up as a 64-years-old male participant (No.6) said: *"If I had to pay out of my pocket, I would die rather than use up all family money. The surgery is super expensive. Even after government subsidized, I still have to loan some money for the extra cost".*

Theme 4: Acceptance of new identity

Lots of sudden changes occurred after oral cancer. The outlook of patients' faces had changed after oral and facial surgery or radiotherapy. They may lose all their teeth, or part of their tongue, or part of facial and oral bone, or end up with distorted lips and faces. They could not return to previous lifestyles. Face and facial expressions make a person's personality, therefore, oral cancer patients had to adjust to their new identity after cancer treatment. The acceptance from family and community members protects patients from mental illness, and all survivors tried to pass the encouragement to other patients if they had chances. As one of female survivor (No.3) used her cancer experiences to change cancer stigma: *"Whoever said cancer patients will always die, come to see me now! I will assure you that cancer patients can survive with good life though".* Sometimes hospital staffs asked the experiences of participants to encourage new cancer patients. They were proud to switch their position from patients to supporters as one male patient (No.7) who had partial glossectomy and radiotherapy stated: *"I felt good after I was done with radiotherapy. I knew I was completely healed. Doctor often asked me to talk to other cancer patients to make them calm. It might because I have calm personality. I was not worried when I went to hospital. When I walked out from radiotherapy room, other patients often asked how I felt. I always told them that radiotherapy is not harmful. I encouraged everyone and told them they will get better soon after therapy, like me".*

Oral cancer patients shared their own experiences, empathy and care to other cancer patients. They did it while waiting in front of doctor's room, while waiting for radiotherapy, or even when they were admitted in inpatient ward as a 64-year-old male participant (No.6), who used to be village volunteer, told about his life in the hospital: *"I have to go for five or six surgeries in this two-years. Lately, I went to hospital by myself. I do not feel fear*

or bore. I have friends there. Nurses told other patients that I was leader of that ward and I will help nurse to check on other patients. I used to be village volunteer and I feel good that my experiences could help other people". Another 69-year-old female participant (No.3) proudly told us about her personality while waiting for radiotherapy: "When I waited in front of radiotherapy room, I always advice newly come patients to frequently sip water. It will help your throat or mouth to not getting too dry. I encourage other cancer patients to get through it with me".

All Participants do not want to become families' burdens, so they try to help themselves by practicing their own daily activities. A male participant (No.4) who had finished treatment 5 years prior, told us about his duty in family's grocery shop: "After recovered, I help my wife doing house works. I wake up early and prepare our shop before we open it in the morning. I do not want to stay without doing anything. I know that I cannot work as I did before, but I will do everything I can. Sometimes newly diagnosed cancer patients come to me to ask for advice. Now I have my new duty as a supporter for those in dire need. I'm proud of myself". Another 69-year-old female patient (No.3) who had surgery on her face 11 years ago said: "I am completely healed. I can go everywhere I want. I just visit my nephew last month in the other town. I can take a long trip now and I'm happy with my life".

According to all themes, the concept of good quality of life emerged from all participants were noted as: "to live with cancer without suffering from pain, not become a family's burden, be able to practice daily activities, receive a good care from medical experts, being accepted for the new identity, being protect by family and community network, and be able to do merit for spiritual care".

Discussion

Quality of life in sick person is the way individuals rank their health status in the context of culture and value systems in which they live. Sickness and illness are not only biomedical symptoms, but a social meaning of experiences. A consequence is attached to the healing process in social construction.^(1,3,31,32) Patients may compare their health status to social standards or to their own health prior to sickness. Thus, quality of life of oral cancer patients is an individual's perspective of life after cancer in the context of their own social world. In this study, patients'

concerns related to quality of life including (1) ability to cope with cancer under the supportive cultural medicine, (2) family support and social network, (3) accessibility and availability to medical care, and (4) acceptance of new identity. The meaning of quality of life was analyzed from oral cancer's experiences in a context of northern Thailand healing culture. All participants lived in large families with middle to low-income. They were born and grew up in the same cultural environment and all explained their cancer as a karma-related origin. To people in this area, social meaning of cancer was attached firmly to Buddhist's explanation that was revealed in a healing pattern of all patients.

Due to the sociocultural meaning of oral cancer, pluralistic medicine plays an important role in the oral cancer healing process. Cultural medicine assort in popular and folk sectors become part of medical realities in these communities. Culture plays a role in illness healing and creates meaning of being sick and healed.⁽¹⁾ The medical systems of all ethnic groups are filled with a variety of cultural related activities. Appearing in various cultures such as witchcraft in African society, indigenous doctors in Asian countries, Ayurveda medicine in Central Asia, Chinese style doctors in China or religious rituals in Thailand are examples of cultural medicine that are indulged in many parts of human communities.^(2,3,12,13,33) Medical system is a dynamic and socialistic process that changes over time to serve for illness management for community members. In our study, oral cancer patients used pluralistic medicine based on their explanations to manage their illness. They believed that karma was the cause of illness; therefore various cultural activities such as rituals, healers, witchcrafts, and religious related activities were involved in the coping process. Although they strongly trusted the wisdom of their doctors and the power of modern medicine, the stigma and myths of cancer still influenced their believes, attitudes, and values of treatment evaluation. In these cases, biomedicine saved patients' life while cultural medicine healed patients' mind, social, and soul. Therefore, living in the supportive environment where patient's meaning of disease was accepted and being responded, help patients during the coping process.

Supports from patients' social network was another factor that brought patients back from crisis and facilitated a new identity in society for survivors. Many participants

had performed risk behaviors for long periods of time prior to cancer diagnosis. Most of them used to smoke or currently smoke and consume alcohol. Having a lower level of education and fear of cancer stigma were found to be the socioeconomic-related causes of late diagnosis in most patients in this study. According to Conway *et al.*, people with low level education and low socioeconomic status had a higher risk of oral cancer compared to higher educated and higher socioeconomic groups.⁽³⁴⁾ Most of oral cancer patients had visited doctors at the late stage of cancer thus resulting in short survival time and low survival rate. Having low knowledge about potentially malignancy disorders and stigma of deadly cancer may have obscured oral cancer patients from early diagnosis.⁽³⁵⁻³⁷⁾ Somehow, the strongest characteristic of the suburb communities is the tied social networks between community members. The performances of true care and supports from families and neighbors improved patients' quality of life.

All participants agreed that the encouragement from their loved ones was the most important factor to support their quality of life. Patients evaluated their quality of life through their interactions with people in their community networks.^(4,7,26) Social structure in this area allowed people to get closer to their networks whenever they fell into serious situations. There was a tied relationship among community members that let them righteously gather when someone in the community fell into life crisis. We also found that faith in religious and local traditional practices are aspects of their community culture that constructed this close relationship between people in community networks. One of the hardest issues for survivors was to find their new position in society^(8,23,26,38), as they may have distorted faces, strange voices, different ways to eat, and be too weak to work as they used to be. The performance of understanding and acceptance from families and people in patient's networks helped them to find values of themselves.^(4,5,8,39)

This study pointed out that good management of and access to expertized cancer medical care, reinforced social network, and access to pluralistic medicine are factors that lead patients to positive coping strategies. Positive coping resulted in positive appraisal on quality of life⁽⁴⁰⁻⁴²⁾. Quality of life evaluation depended on patient's perspectives.^(17,43) Patients with advanced cancer but positive coping styles may have better quality of life than patients

with earlier stage but negative coping styles.^(10,40,44) Oral cancer survivors had a significantly harder coping pattern compared to other cancer survivors^(15,27,40,45) because of the difficulty in adjusting to new facial appearances and distorted oral functions. Oral surgery, radiotherapy, and chemotherapy caused the malfunction of facial and oral organs such as xerostomia, oral mucositis, change in voice and speech, dysgeusia, dysphagia, nausea, vomiting, weight loss, and fatigue by which all reduced patient's quality of life from the beginning of cancer treatment.^(14,46) Similar to other head and neck cancer studies, survivors of our study felt better within about 6 months to 1 year after treatment.^(15,27,40,45) With the help from public policy and the social construct of their communities, patients found new social position and the meaning of their illness. When they realized their potential to help other cancer patients, they judged quality of life in a good direction.

In summary, quality of life in oral cancer patients is related to both biomedical and cultural health care systems. Cultural medicine plays an important role on mental, spiritual, and social healing while biomedicine restore body and mind sickness. The social construct and public policy support access to care, budget needs, and construct the connection of people in social network. We conclude from the results that a good quality of life in cancer patient's perspective was *"to live the life as close as they used to be surrounded by their beloved families and friends in the supportive environments"*. Oral cancer patients received a good quality of life when they were fulfilled with both scientific and sociocultural meaning of healing.⁽³¹⁾

Conclusions

Quality of life in oral cancer depends on patients' perspectives of their own health status and the potential to survive with the less distortion as little as possible. The explanations on illness and healing in oral cancer have been influenced by community culture by which offering meaning of cancer and healing systems to social members. As people attach their by to community culture, The quality of life is be judged by both biomedical and sociocultural aspects. For the quality of life, government should manage access and improve availability to cancer expertized medical care regardless of patient's economic status. Moreover, cultural related activities in community should be promoted to maintain the tied relationship of people in

community. Furthermore, supportive cultural medicine should be considered as part of patient's care together with advanced modern medicine in order to bring patients with oral cancer back to society with a good quality of life.

Acknowledgements

We are grateful for patients and their families for kindly sharing their time and their experiences. We would like to also thank Prof. Dr. Anak Iamaroon, Dr. Chantana Ungchusak, and Asst. Prof. Dr. Songvuth Tuongratanaphan, for their advice on this study. This research was funded by a grant from Graduate Faculty of Dentistry, Chiang Mai University.

References

- Kleinman A. Concepts and a model for the comparison of medical systems as cultural systems. *Soc Sci Med.* 1978;12(2):85-95.
- Kleinman A. *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry.* Berkeley, Los Angeles, and London: University of California Press; 1980.
- Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Ann Intern Med.* 1978;88(2):251-8.
- Hu TW, Cooke M, McCarthy A. A qualitative study of the experience of oral cancer among Taiwanese men. *Int J Nurs Pract.* 2009;15(4):326-33.
- Allen JD, Savadatti S, Levy AG. The transition from breast cancer 'patient' to 'survivor'. *Psychooncology.* 2009; 18(1):71-88.
- van der Molen B. Relating information-needs to the cancer experience. 1. Jenny's story: a cancer narrative. *Eur J Cancer Care (Engl).* 2000;9(1):41-7.
- Cheng CH, Wang TJ, Lin YP, Lin HR, Hu WY, Wung SH, *et al.* The illness experience of middle-aged men with oral cancer. *J Clin Nurs.* 2013;22(23-24):3549-56.
- Costa EF, Nogueira TE, de Souza Lima NC, Mendonca EF, Leles CR. A qualitative study of the dimensions of patients' perceptions of facial disfigurement after head and neck cancer surgery. *Spec Care Dentist.* 2014;34(3):114-21.
- Pulte D, Brenner H. Changes in survival in head and neck cancers in the late 20th and early 21st century: a period analysis. *Oncologist.* 2010;15(9):994-1001.
- Blanchard P, Volk RJ, Ringash J, Peterson SK, Hutcheson KA, Frank SJ. Assessing head and neck cancer patient preferences and expectations: A systematic review. *Oral Oncol.* 2016;62: 44-53.
- Shield KD, Ferlay J, Jemal A, Sankaranarayanan R, Chaturvedi AK, Bray F, *et al.* The global incidence of lip, oral cavity, and pharyngeal cancers by subsite in 2012. *CA Cancer J Clin.* 2017;67(1):51-64.
- Hunt LM. Moral reasoning and the meaning of cancer: causal explanations of oncologists and patients in southern Mexico. *Med Anthropol Q.* 1998;12(3):298-318.
- Daher M. Cultural beliefs and values in cancer patients. *Ann Oncol.* 2012; 23(suppl 3):66-69.
- Chandu A, Smith AC, Rogers SN. Health-related quality of life in oral cancer: a review. *J Oral Maxillofac Surg.* 2006;64(3):495-502.
- Murphy BA, Ridner S, Wells N, Dietrich M. Quality of life research in head and neck cancer: a review of the current state of the science. *Crit Rev Oncol Hematol.* 2007;62(3):251-67.
- Ojo B, Genden EM, Teng MS, Milbury K, Misiukiewicz KJ, Badr H. A systematic review of head and neck cancer quality of life assessment instruments. *Oral Oncol.* 2012;48(10):923-37.
- WHO Health Promotion Glossary 1998 [Internet]. World Health Organization. 1998 [cited 01-01-2019]. Available from: <https://www.who.int/healthpromotion/about/HPG/en/>.
- Imsamran W, Pattatang A, Supattagorn P, Chiawiriyabunya I, Namthaisong K, Wongsena M, *et al.* Cancer in Thailand: Vol. IX, 2013-2015. Bangkok, Thailand: New Thammada Press (Thailand); 2018.
- Tangjaturonrasme N, Vatanasapt P, Bychkov A. Epidemiology of head and neck cancer in Thailand. *Asia Pac J Clin Oncol.* 2018;14(1):16-22.
- Komolmalai N, Chuachamsai S, Tantiwipawin S, Dejsuvan S, Buhngamongkol P, Wongvised C, *et al.* Ten-year analysis of oral cancer focusing on young people in northern Thailand. *J Oral Sci.* 2015;57(4):327-34.
- Iamaroon A, Pattanaporn K, Pongsiriwet S, Wanachantararak S, Prapayasatok S, Jittidecharaks S, *et al.* Analysis of 587 cases of oral squamous cell carcinoma in northern Thailand with a focus on young people. *Int J Oral Maxillofac Surg.* 2004;33(1):84-8.
- Vakharia KT, Ali MJ, Wang SJ. Quality-of-life impact of participation in a head and neck cancer support group. *Otolaryngol Head Neck Surg.* 2007;136(3):405-10.
- Katz MR, Irish JC, Devins GM, Rodin GM, Gullane PJ. Psychosocial adjustment in head and neck cancer: the impact of disfigurement, gender and social support. *Head Neck.* 2003; 25(2): 103-12.
- Moore KA, Ford PJ, Farah CS. "I have quality of life... but...": Exploring support needs important to quality of life in head and neck cancer. *Eur J Oncol Nurs.* 2014;18(2):192-200.
- Jabbour J, Milross C, Sundaresan P, Ebrahimi A, Shepherd HL, Dhillon HM, *et al.* Education and support needs in patients with head and neck cancer: A multi-institutional survey. *Cancer.* 2017;123(11):1949-57.
- O'Brien KM, Timmons A, Butow P, Gooberman-Hill R, O'Sullivan E, Balfé M, *et al.* Associations between neighbourhood support and financial burden with unmet needs of head and neck cancer survivors. *Oral Oncol.* 2017;65:57-64.

27. So WK, Chan RJ, Chan DN, Hughes BG, Chair SY, Choi KC, *et al.* Quality-of-life among head and neck cancer survivors at one year after treatment--a systematic review. *Eur J Cancer.* 2012;48(15):2391-2408.
28. Benner P. Quality of life: a phenomenological perspective on explanation, prediction, and understanding in nursing science. *ANS Adv Nurs Sci.* 1985;8(1):1-14.
29. Shosha GA. Employment of Colaizzi's strategy in descriptive phenomenology: a reflection of a researcher. *Eur Sci J.* 2012;8(27):31-43.
30. Loh J. Inquiry into issues of trustworthiness and quality in narrative studies: a perspective. *TQR.* 2013;18(65):1-15.
31. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. a conceptual model of patient outcomes. *JAMA.* 1995;273(1):59-65.
32. Ventegodt S, Merrick J, Andersen NJ. Quality of life theory I. The IQOL theory: an integrative theory of the global quality of life concept. *ScientificWorldJournal.* 2003;3:1030-40.
33. Juntaramano S, Swangareeruk J. The wisdom of indigenous healers in cancer treatment. *JTTAM.* 2017;15(3):286-300.
34. Conway DI, Petticrew M, Marlborough H, Berthiller J, Hashibe M, Macpherson LM. Socioeconomic inequalities and oral cancer risk: a systematic review and meta-analysis of case-control studies. *Int J Cancer.* 2008;122(12):2811-9.
35. Scott SE, Grunfeld EA, Main J, McGurk M. Patient delay in oral cancer: a qualitative study of patients' experiences. *Psychooncology.* 2006;15(6):474-85.
36. Peacock ZS, Pogrel MA, Schmidt BL. Exploring the reasons for delay in treatment of oral cancer. *J Am Dent Assoc.* 2008;139(10):1346-152.
37. Jafari A, Najafi S, Moradi F, Kharazifard M, Khami M. Delay in the diagnosis and treatment of oral cancer. *J Dent (Shiraz).* 2013;14(3):146-50.
38. van der Molen B. Relating information needs to the cancer experience. 2. Themes from six cancer narratives. *Eur J Cancer Care (Engl).* 2000;9(1):48-54.
39. Bowman KF, Rose JH, Deimling GT. Appraisal of the cancer experience by family members and survivors in long-term survivorship. *Psychooncology.* 2006;15(9):834-45.
40. Llewellyn CD, McGurk M, Weinman J. Head and neck cancer: to what extent can psychological factors explain differences between health-related quality of life and individual quality of life? *Br J Oral Maxillofac Surg.* 2006;44(5):351-7.
41. Horney DJ, Smith HE, McGurk M, Weinman J, Herold J, Altman K, *et al.* Associations between quality of life, coping styles, optimism, and anxiety and depression in pretreatment patients with head and neck cancer. *Head Neck.* 2011;33(1):65-71.
42. Schroevers MJ, Kraaij V, Garnefski N. Cancer patients' experience of positive and negative changes due to the illness: relationships with psychological well-being, coping, and goal reengagement. *Psychooncology.* 2011;20(2):165-72.
43. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA.* 1999;281(2):163-168.
44. van Deudekom FJ, Schimberg AS, Kallenberg MH, Slingerland M, van der Velden LA, Mooijaart SP. Functional and cognitive impairment, social environment, frailty and adverse health outcomes in older patients with head and neck cancer, a systematic review. *Oral Oncol.* 2017;64:27-36.
45. Rieke K, Schmid KK, Lydiatt W, Houfek J, Boilesen E, Watanabe-Galloway S. Depression and survival in head and neck cancer patients. *Oral Oncol.* 2017;65:76-82.
46. Bressan V, Stevanin S, Bianchi M, Aleo G, Bagnasco A, Sasso L. The effects of swallowing disorders, dysgeusia, oral mucositis and xerostomia on nutritional status, oral intake and weight loss in head and neck cancer patients: A systematic review. *Cancer Treat Rev.* 2016;45:105-119.