

Live with mask and guilt: A qualitative study on experiences of stigma among postoperative oral cancer patients in China

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Research Article

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Abstract

Objectives: To explore the drives, manifestations and coping strategies of stigma in postoperative oral cancer patients to provide a reference for the formulation of targeted intervention measures.

Methods: Using a phenomenological approach, we enrolled 15 postoperative oral cancer patients in a certain Grade a hospital from 10 March 2021 to 30 June 2021 in Hunan Province, China. Semi-structured interviews were conducted. The interview data were analyzed using a framework analysis based on qualitative content analysis methods. This study aligns with the COREQ checklist.

Results: The stigma experience of postoperative oral cancer patients can be divided into 3 themes: (1) drivers (internal factors and external factors); (2) manifestations (isolation, feeling of guilt, feeling of inferiority and the experience of discrimination); (3) coping strategies (self-adjustment, seeking social support and enhance physical quality).

Conclusion: Postoperative oral cancer patients lived with mask and guilt, and experienced multiple forms of discrimination. Further work is needed to increase education and awareness about oral cancer to guide them to take positive coping and reduce stigma.

1 Background

Oral cancer is ranked as the eighth most frequently diagnosed malignancy^[1] and is extensively widespread in many developing countries compared with developed countries^[2]. As reported by GLOBOCAN 2018^[3], more than 350,000 cases of oral cancer were diagnosed worldwide, and approximately 180,000 people died from it each year. According to the latest Cancer Registry Report released by the National Central Cancer Registry of China (NCCR) in 2020, there were about 4.29 million new cancer cases and 2.81 million cancer deaths in China, while there were about 48,100 new cases and 22,100 deaths from oral and oropharyngeal cancer, accounting for 1.12% and 0.79% of all new cancer cases and deaths, respectively in 2015^[4-5]. Oral cancer has become a global health problem owing to its relatively high morbidity and mortality rates.

At present, surgical treatment is the mainstay of therapy for patients with oral cancer^[6]. Surgical treatment for oral cancer consists of removing the tumor with or without removing lymph nodes in the neck^[7]. This may impair the function and appearance of the patient's face, neck, and mandible, which negatively affects their postoperative body image and ability to open their mouth, speak, chew, and swallow^[8]. These physiological changes are visible to the public and may result in the disqualification of individuals from full social acceptance, which Goffman defined as stigma in 1963^[9].

Stigma is one of the psychosocial issues faced by people with cancer. It usually refers to the perception of a person as different from others in the community^[10]. This psychosocial concept is a process of social tagging and a set of negative attitudes, beliefs, thoughts, and behaviors toward a person

experiencing different situations^[11] Compared with patients with other types of cancer, patients with oral cancer face uniquely difficult challenges, including issues relating to the loss of basic oral functions and limited ability in daily activities, which can significantly contribute to patient's stigma^[12-13].

Studies have shown that some stigmatized patients avoid social interaction or even completely isolate themselves^[14]. Stigmatized patients may feel ashamed and deteriorate their mental state when facing discrimination from others^[15]. These negative attitudes can lead to fear, avoidance of communication with others, and the feeling of distinction^[11]. The prevailing stigma of oral cancer is that it is a preventable, self-inflicted disease caused by bad living habits^[16]. This stigma associated with bad living habits has had a negative impact on the psychosocial health of patients. Consequently, stigma in postoperative oral cancer patients is a serious problem and an obstacle to achieving the goals of the individual's life during return to normal life.

Coping refers to an individual's adjustment behavior to changes, which can regulate their physical and mental responses related to stressful events^[17]. The topic of coping in postoperative oral cancer patients remains an area to explore. Coping strategies play a significant role in one's ability to adapt to stressful life conditions^[18]. According to systematic review, the stigma suffered by oral cancer patients not only led to the deterioration of the disease, but also had a significant negative impact on mental health and quality of life. Appropriate coping strategies were critical in mitigating the adverse effects brought by stigma.

In summary, there was a body of quantitative research documenting that stigma was experienced by oral cancer patients, including those living in China. Qualitative studies can offer deep insights into individuals' experiences and provide a better understanding of stigma from the perspective of people suffering from it. There were few qualitative research studies on living with oral cancer that address the experience of living with the stigma of this extremely complex multivariate disease. The objective of this study was to describe the drives, manifestations and coping strategies of stigma in postoperative oral cancer patients through semi-structured and individual in-depth interviews, in order to provide a reference for the formulation of targeted intervention measures.

2 Methods

2.1 Design

The aim of this study was to provide an in-depth description of the stigma experienced by postoperative oral cancer patients, an area about which currently little is known. As such, a qualitative descriptive study was used to provide a beginning understanding of these issues. The current research was approved by the Ethical Committee of Central South University (No. E202060).

2.2 Participants

Patients were recruited from a certain Grade a hospital in Hunan Province, China. A purposive convenience sampling strategy was used. The inclusion criteria were patients who were (1) aged 18 or older; (2) diagnosed with oral cancer; (3) survived more than three years after surgery; (4) aware of their own diagnosis; and (5) able to accurately and fluently answer questions. The exclusion criteria were patients who had (1) any history of mental or cognitive disorders or (2) comorbidity with other oral diseases or other cancers. Participants' demographic and clinical characteristics were also collected, such as participants' age, sex, marital status, education level, occupation and pathological type.

2.3 Data collection

The data were collected in the form of Semi-structured and individual in-depth interviews. Two nurses-in-charge gave recruitment brochures to potentially eligible people. Patients gave verbal consent to be contacted by a researcher, who then obtained written informed consent and arranged an audio-recorded interview. Interviews were conducted at a time and location convenient to the participant. The interviews were between 30 and 45 minutes in duration. According to the relevant literature on stigma and the relevant principles of qualitative interviews^[8], a semi-structured interview guide was used (Table 1). All the interviews were recorded using a digital voice recorder, and the participants' nonverbal behaviors and the interviewers' thoughts on the interviews were also recorded as field notes.

Table 1
Semi-structured interview guide.

NO.	Question
Question1	What did your psychological feelings after the diagnosis of the disease and operation?
Question2	What unfair treatment did you suffer?
Question3	What caused you to be treated unfairly?
Question4	What kind of psychological or emotional experience did you have when you were treated unfairly?
Question5	How did this psychological or emotional experience affect your work, study and life?
Question6	How did you deal with unfair treatment?

2.4 Data analysis

Within 24 hours after the interview, data were audio-recorded and transcribed verbatim. QSR International's NVivo 11.0 software was used to store transcripts and manage codes. During this process, investigator triangulation was used and codes were reviewed by two additional investigators to confirm the interpretation and refine the coding structure^[19]. The interview data were analyzed using a framework analysis

based on qualitative content analysis methods^[20]. Seven discrete stages were included in this method, which aims to summarize and classify all data. Eventually, a methodical and rigorous thematic

framework was formed.

3 Results

Between 10 March and 30 June 2021, 25 people were referred, of whom 17 consented to participate. Two people who consented subsequently withdrew as they were no longer interested in participating. Participants ranged in age from 32 to 56 years. Most were male and married. Demographics are presented in Table 2.

All participants described their experience of stigma. The stigma experience of postoperative oral cancer patients can be divided into 3 themes: (1) drivers (internal factors and external factors); (2) manifestations (isolation, feeling of guilt, feeling of inferiority and the experience of discrimination); (3) coping strategies (self-adjustment, seeking social support and enhance physical quality). The themes and categories that emerged from the analysis are shown in Figure 1. These are further described below.

Table 2
Demographic characteristics of the participants (N=15)

NO.	Age(years)	Sex	Marital status	Education	Occupation	Pathological type
1	43	Male	Married	College	Doctor	T
2	56	Male	Married	Primary school	Farmer	T
3	50	Male	Married	Middle school	Worker	T
4	42	Male	Married	Middle school	Farmer	B
5	48	Male	Married	College	Office clerk	B
6	43	Male	Married	Primary school	Worker	T
7	52	Male	Married	Middle school	unemployed	T
8	48	Male	Married	Primary school	Unemployed	T
9	36	Male	Married	High School	Unemployed	T
10	32	Male	Unmarried	College	Office clerk	T
11	38	Female	Married	College	Freelance work	T
12	35	Male	Married	College	Programmer	T
13	55	Male	Married	Primary school	Farmer	T
14	38	Male	married	College	Individual	B
15	42	Male	married	Middle school	Worker	T

Note: Pathological type: T = Tongue cancer, B = Buccal carcinoma.

3.1 Drivers

There were two categories. The first categories was internal factors, including shape change, impaired physical function, and financial stress. The second categories was external factors, including excessive attention from others, misconceptions by medical staff, social stereotypes.

3.1.1 Internal factors

3.1.1.1 Shape change

The pathological types of oral cancer patients were mainly tongue cancer and buccal carcinoma. Surgery was more traumatic to the patient's appearance. After surgery, patients were prone to scarring on their faces. Some patients said they wore masks when they went out for fear of scaring others. Shape change was an important cause of stigma.

"After the operation, the skin did not recover well, and my appearance became very poor." (N4)

"Once, when I was on the elevator, the neighbors saw my scars and didn't want to come in." (N14)

3.1.1.2 Impaired physical function

The patient's physical condition deteriorated after the illness and there was no way to do some work. Their speech, swallowing, and other functions were severely impaired. These affected the patient's daily life.

"I usually carry a little paper in my pocket and wipe the saliva at any time." (N3)

"I did not speak clearly after the surgery, which had a great impact on my current work life." (N4)

3.1.1.3 Financial stress

Most of postoperative oral cancer patients came from rural areas, had low education, did not have stable jobs, and did not have enough money to see a doctor. In addition, some patients needed to be cared for and their caregivers were unable to work, which reduced the family's financial resources.

"The doctor said it would cost a lot of money, and my family didn't have enough money to treat me. (Sigh)" (N3)

"I did not have a job anymore, I spent many money on treatment, and My wife couldn't work to take care of me." (N7)

3.1.2 External factors

3.1.2.1 Excessive attention from others

Many patients described that they were overly cared for by family and friends. Families were reluctant to let patients do anything, even if it is within the patient's ability. Friends also tried to accommodate them as much as possible to avoid embarrassing them. At the same time, co-workers inadvertently mentioned things about their illness and always helped share their work, even if they can do it independently. These had become their troubles. For patients with independent personality and self-awareness, the excessive care of relatives and friends damaged their self-esteem and affected their self-cognition and evaluation.

"My son told me to rest at home and not to go out to work." (N2)

"A lot of my colleagues knew I was sick and wanted to help me share the work, and I knew they care about me, but it made me a little embarrassed." (N10)

3.1.2.2 Misconceptions by medical staff

Excessive pressure and criticism from medical staff was also responsible for the formation of patient stigma. Some patients said that doctors or nurses only care about whether they have completed the post-discharge review as required and did not consider the actual needs and abilities of patients from the perspective of patients.

"The doctor asked me why I come for review after such a long time. I was also under great pressure and cannot hang up the number." (N9)

"I was a bit busy some time ago. After a long time, I went to check my body for fear that medical staff would think that I did not pay attention to my body, and I could do nothing." (N12)

3.1.2.3 Social stereotypes

There was fear that cancer could be transmitted through sharing eating utensils, sleeping in the same room, playing with children, through cooking food or just general socializing. This fear of cancer being transmissible even extends to those living with cancer. It was believed that oral cancer must be caused by the patient's unhealthy lifestyle habits, such as "eating betel nut" mentioned in N2 and N9. In addition, a strong belief that cancer is incurable and those who have it will die quickly, permeated the transcripts. The fear of illness and death also led to avoidance of the person with cancer, both within and outside the family.

"Because friends think that the disease will spread to them, while eating, talking, they have that kind of fear; even I am unaware whether this will spread like that." (N5)

"Some people say that I did something bad to get this disease." (N9)

3.2 Manifestations

Drivers and manifestations (forms) of stigma were closely linked in the transcripts, often within the same sentence. The manifestations of stigma, whether anticipated or experienced, grouped broadly into isolation, feeling of guilt, feeling of inferiority, the experience of discrimination.

3.2.1 Isolation

The most commonly described forms of stigma were psychic, physical and social isolation. Patients wore masks to live without wanting to be honest about their inner thoughts and feelings, and became adept at disguising their emotions. Meanwhile, patients were afraid to go out and were reluctant to participate in social events. As described earlier, the public were worried that the disease was contagious, avoidance manifested through behaviors such as keeping patients in a separate room, providing separate food as well as eating utensils, no longer visiting people with cancer in their house or avoiding them in public.

“The disease is also not known if there is a possibility of transmission to other people. Some people are afraid to be close to me in rural areas.” (N4)

“It feels like some people hate me, I still have to wear a mask when I go out, and many relationships are estranged.” (N5)

3.2.2 Feeling of guilt

Patients suffered from psychological pressure and adverse reactions in spirit, mainly manifested as guilt. They were worried about being a burden on their families and unable to fulfil their social responsibilities. Some patients showed emotions of self-blame and remorse and began to reflect on the causes of their illness. They believed that their disease is caused by these poor habits and lifestyle.

“I often do some housework at home.”(N7)

“I felt so sorry for my wife, who had to take care of me and our kids.”(N12)

“I heard the doctor said that chewing betel nut may have an effect on my disease and I hurt myself.” (N15)

3.2.3 Feeling of inferiority

Changes in the body made the patient had a sense of inferiority. They thought themselves as no longer a complete person. As a result, patients had the idea that they were inferior to others and lacked confidence in life. Some patients developed self-doubt for a long time and dared not to return to social.

“I envy people who are in good health, and I feel inferior to others.” (N11)

“I do not know why I became like this, and I do not know what I can do in the future” (N6)

3.2.4 The experience of discrimination

In this interview, the patient talked about his experience of social inequality. Patient mentioned that they would likely no longer be able to work outside the home, either because they were too weak, or because employers would discriminate against them and not allow them to work. There were also patients who

continued to work described the unfair treatment during their work. Another described manifestation of stigma throughout the transcripts was verbal abuse towards people living with cancer, which was expressed in varied ways, such as teasing, scolding and blaming. And beyond that, patients mentioned that it would affect their families (secondary stigma). The destruction of children's life chances, especially their marriage prospects.

"I was fired, and the boss told me to go back and rest." (N7)

"I was particularly angry when I had a fight with someone who said I deserved this disease."(N13)

3.3 Coping strategies

Patients faced the psychological pressure, public opinion pressure and life pressure brought by the disease itself and the stereotypes of the surrounding people. Their coping styles varied from person to person. The coping strategies of stigma mainly were three categories: self-adjustment, seeking social support, and enhance physical quality.

3.3.1 Self-adjustment

Some patients adopted self-adjustment methods to cope with various troubles. They were mainly through self-encouragement and diversion. It was beneficial for patients to maintain a positive and optimistic attitude to cope with the stigma caused by the disease.

"You have to overcome yourself before you can go out of the shadow. I believe I can do it." (N14)

"I like to play cards and chess when I'm in a bad mood. I don't think about my health when I'm busy."
(N13)

3.3.2 Seeking social support

Many patients took the initiative to seek help from family and friends when they were in a bad mood. Patients appreciated the social support they accessed, and were aware of the positive impact on them and their family. They commented that engaging social support improved their quality of life and contributed to successfully managing their familial relationships. While most participants were able to access support that adequately met their needs, some reported difficulties accessing care.

"Sometimes I am in a bad mood and worry about the recurrence of the disease, and I will take the initiative to seek comfort from my husband. In addition to that, I also like to ask my friends to go square dancing to relieve anxiety."(N11)

"I found that I took the initiative to ask my family for help, and they would all be happy, which made me feel that family life was very warm."(N13)

"I wanted to check my body again but I couldn't hang up the check number." (N14)

3.3.3 Enhance physical quality

In addition to maintaining a positive and optimistic mindset, many patients were also aware of the importance of strengthening physical fitness. They began to change their previous bad habits. Some patients also took the physical exercise approach. Some also improved their constitution through food and medicine. These methods can help them actively cope with the impact of the disease.

“I now take a walk every day after a meal for about half an hour.”(N5)

“In addition to taking medicine prescribed by the doctor, I also take some traditional Chinese medicine to improve my immunity.”(N8)

“I successfully quit smoking, got away from betel nuts. It feel good to go to the park every day to work out”.(N15)

4 Discussion

By delving into the nature of stigma in China and offering an in-depth, conceptually grounded description of the drivers and manifestations of stigma, we have gone beyond prior research that has primarily pointed to its existence. To this end, we attempted to build a conceptual frame of stigma through eliciting patients' experiences of stigma. The conceptual framework includes the following three parts: drivers, manifestations, and coping strategies.

We found that shape change and impaired physical function were important drivers of stigma, which was consistent with previous findings^[21]. Many patients were prone to stigma owing to body image loss, reduced self-esteem, and a sense of shame, and postoperative oral cancer patients were especially susceptible because of the facial deformity and dysfunction they experience^[4, 22]. Importantly, facial disfigurement was consistently associated with the development of stigma and the perception of stigma^[23]. In addition, economic pressure is also one of the drivers of patients' stigma. As part of one's personal social resources, a higher income levels can greatly reduce the psychological and financial stress caused by cancer diagnosis and treatment.

The treatment of cancer led to a decline in the patient's ability to take care of themselves and work, and they needed the care of their families and even society^[24]. At the same time, excessive concern from relatives and friends of postoperative oral cancer patients damaged the patient's self-esteem, which affected their self-perception and evaluation. We found that stigma also came from medical staff, which was different from previous studies^[25]. Medical staff had a negative attitude toward predicting and responding to patients' diseases^[26]. In addition, due to the shortage of medical resources, many patients were unable to repeat the examination on time. The loss of identity in health services was the most frightening, as outside respect in society was an important factor in their exposure to the world and their re-engagement.

We also found that social stereotypes play an important role in driving stigma. In traditional Chinese culture, cancer was considered karma in a past life; suffering from cancer was equivalent to being sentenced to death^[27]. The public believed that the emergence of cancer was not only a punishment in the present life, but also a repayment of debts in the previous life, which became “causal reincarnation”^[11]. The public’s incorrect cognition caused stigma in patients. Meanwhile, through in-depth interviews with patients, we found that many people and even the patients themselves sometimes believed that oral cancer is contagious. Due to the influence of public opinion, the cognitive tendency of patients was more serious^[28]. We can spread disease-related knowledge through the government propaganda or the use of the network and correct the public’s misunderstanding of postoperative oral cancer patients.

That cancer stigma was present and manifests in many forms emerged across postoperative oral cancer patients data sets. Patients consistently described acts of social and physical isolation. One of our most important findings was that patients live with mask, they wanted to hide their true feelings, which was different from previous studies^[25]. Communications with others were abandoned as a result of their anxieties and worries. We also found that feeling of guilt and inferiority were manifestations of stigma. Feelings of guilt, shame and blame, depression, low self-esteem, and poor quality of life resulting from oral cancer stigma have been described in previous studies^[29]. Patients’ stigma made patients doubt their own behavioral ability and led to a decline in self-efficacy^[30]. The patients’ experience of discrimination mainly included job loss, verbal abuse, and marriage prospects reduced. It suggests that we can pay more attention to the subjective feelings of patients and implement effective anti-stigma interventions.

The negative emotions caused by the disease in cancer patients led to psychological and social dysfunctions, which can affect the body’s immunity and aggravate the deterioration of the disease^[31]. As a component of individual tools, coping strategies represented efforts made by a patient to deal with distress^[32]. We found that postoperative oral cancer patients adopt positive coping strategies to face stigma, such as self-encouragement and diversion. Furthermore, a lower level of stigma was confirmed to be associated with lower rates of alcohol and cigarette abuse, more frequent exercise and better nutrition^[12]. We found that some patients took traditional Chinese medicine to treat their diseases. The inhibitory effect of traditional Chinese medicine on tumors was reflected at multiple levels and through multiple pathways, the efficacy, safety and mechanism of action need more in-depth experimental research^[33]. Different strategies adopted by patients would result in diverse outcomes. Therefore, it is important for healthcare professionals to help them develop effective coping strategies to reduce the negative consequences of stigma.

Social support can help patients regulate their emotions and problem-solve, which can enhance their resilience when facing stigma and thus provide a buffer from experiencing stress^[34]. We found that family and friends were the major providers of support for postoperative oral cancer patients. Some patients did not want to bother others, and hoped to maintain harmony. Medical staff should encourage patients to seek help voluntarily. We also found that developing collaborative and supportive

relationships with close persons and the medical staff had a vital role in coping and adjustment. Medical staff played a significant role in participants' awareness of psychosocial support services. Many acknowledged that conversations initiated by medical staff were essential for their ability to find services relevant to their psychosocial needs^[35]. Therefore, more social support from the community, family and friends is essential to reduce stigma.

4.1 Study limitations

There were several limitations of the study. The sample size may not be representative of larger populations because the participants came from a single geographical area with similar ethnicity and culture. In addition, the study reports on the self-reported experiences of participants, which were subject to recall bias.

4.2 Clinical Implication

Despite these limitations, our findings have several clinical implications. First, These findings suggest that there were various stigma-driven factors in postoperative oral cancer patients, which can lead to the imbalance of psychosocial function and seriously affect the quality of life of patients. Second, medical staffs should help patients to actively seek social support and cope with the disease, reduce the stigma of patients. Third, through publicity to increase social awareness of oral cancer to encourage society to accept patients and to reduce the driver of patient stigma.

5 Conclusion

Postoperative oral cancer patients clearly articulated that stigma was present in their lives. They lived with mask and guilt, and experienced multiple forms of discrimination. This exploration of the driving factors and stigma manifestations provides insights for future programmatic efforts to reduce stigma and improve access to information, screening and treatment. Further work is needed to increase education and awareness about oral cancer to guide them to take positive coping and reduce the stigma.

Declarations

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Conflicts of interest

The authors declare no competing interests.

Availability of data and material

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Code availability

Not applicable

Authors' contributions

Concept and design:Ye Man,Tan Chuxia. Acquisition, analysis, or interpretation of data:Zhong Chenxi, Mei Ranran ,Yang Ronghong, Wang Dangdang. Drafting of the manuscript:Ye Man,Tan Chuxia. Critical revision of the manuscript for important intellectual content: Deng Xianjiao, Chen Shihao, Li Wei. Statistical analysis: Ye Man,Tan Chuxia. All authors read and approved the final manuscript.

Ethics approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Review Committee of the School of Nursing, Central South University (No. E202060).

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent for publication

Not applicable.

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Figures

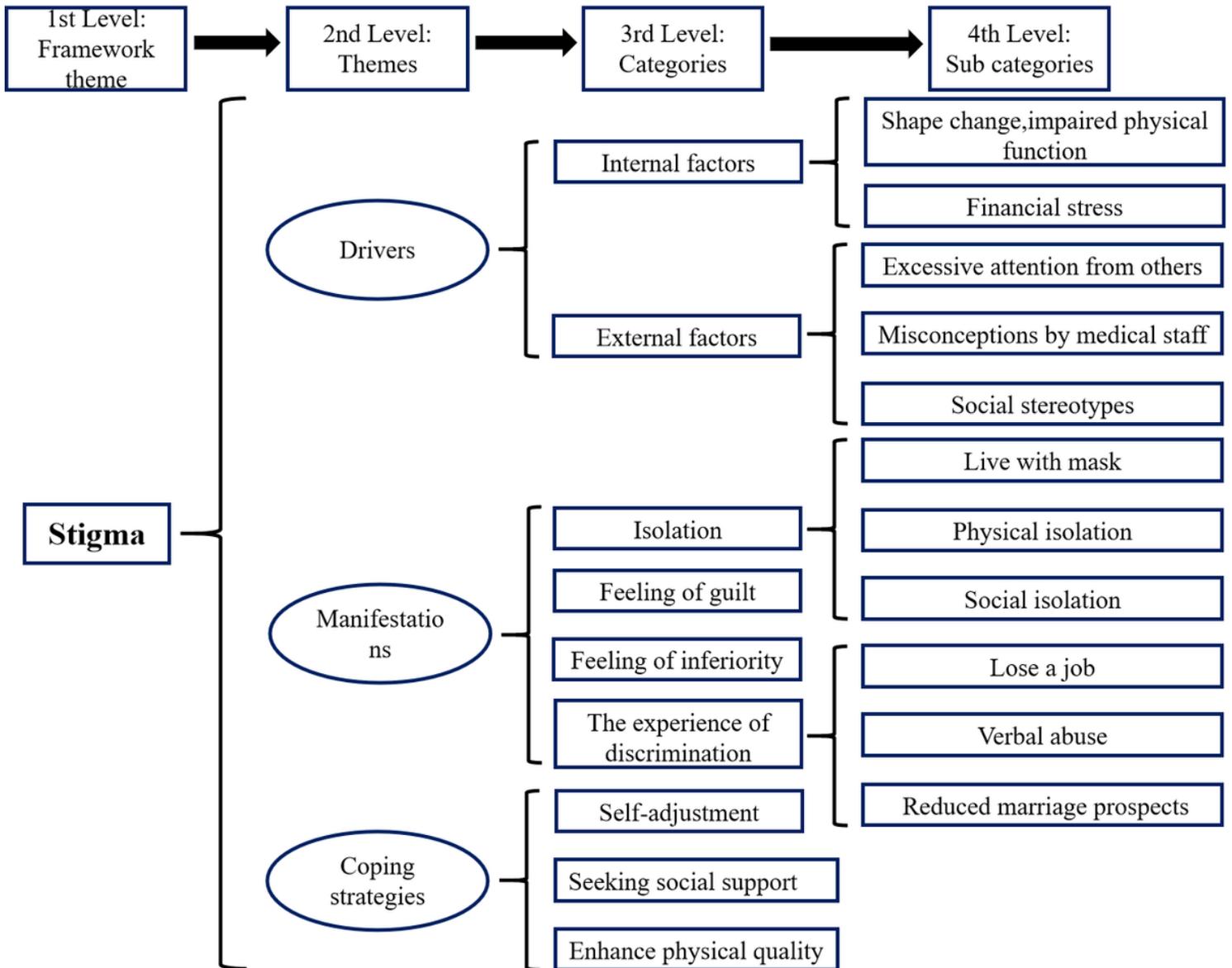


Figure 1

Conceptual framework of stigma among postoperative oral cancer patients