Living in Limbo: Ethics and Experience in a Conversation about Persistent Oral Lesions

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Introduction

In "Living in Limbo: Life in the Midst of Uncertainty," Donald Capps and Nathan Carlin write about "limbo situations" in everyday life. An example of a limbo situation includes the experience of finding oneself out of work or being laid off and not knowing when or if one will find a new job — they call this work-related limbo (1). Another example of a limbo situation involves waiting to get married. Some couples, for example, do not have parental approval to proceed with their wedding plans, and, be-

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Abstract

This case report presents a conversation that the authors had with a patient who is suffering from oral lichen planus and oral cancer. The reason that the authors approached the patient for an interview was to find out why he decided to enroll in an experimental study related to his oral cancer. The patient reported that it was "the waiting" that led him to enroll in this study — that is, the pressure of waiting for oral cancer to re-emerge was simply unbearable, and enrolling in this experimental study enabled him to take a more proactive approach to his illness. The authors view this "waiting" as a "limbo experience" and reflect on the implications of this limbo experience for dental ethics and research ethics.

KEY WORDS:
Oral cancer, oral lichen planus, dental ethics, research ethics, limbo experiences, autonomy, patient preferences

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cause they do not want to alienate themselves from their families and because they also do not want to give up on their relationship, they find themselves in relational limbo. Going through a divorce is another example of relational limbo (2). These authors also include a chapter on illness-related limbo, such as waiting while healthcare professionals try to determine one's diagnosis and prognosis (3). Their book is filled with real life stories of people living in limbo, and they write about how these persons have made the best of these states, situations that seem to be more or less universal to all stages and walks of life (4).

In their book, Capps and Carlin wrote about limbo situations from a theological perspective for a religious audience (5). In this article, we draw on their ideas, but we do not write from a theological perspective, and we write for a clinical audience. And while these authors did apply the idea of limbo to illness, they did not think about illness-related limbo in terms of bioethics. Here we apply the idea of limbo to dental ethics, a subfield of bioethics, and we do so by interpreting a conversation that we had with a patient who has oral cancer. We begin by reviewing the clinical details of this patient because these details will help orient readers to the case. We then view the case in terms of Capps and Carlin's notion of limbo so as to bring certain ethical issues to light that otherwise usually go unnoticed because there is not a vocabulary in dental ethics, or in bioethics, to talk about such situations. We argue that the notion of limbo can help healthcare professionals understand autonomy and patient preferences more fully. The tone of this essay, we also want to point out, is conversational, because this, we felt, would reflect the tone of our conversation with the patient.

Background Information

When one of the authors (CF) mentioned to the patient that she would be interested in telling his story, he immediately agreed. We later followed up with the patient, and explained that we would like to interview him and to write about his experience in a journal article. The patient remained enthusiastic and gave verbal consent for this case report.

In order to maintain the privacy of the patient, he will be referred to as Mr. OC. His story is a long and complicated one because it is dealing with two different oral diseases, which may or may not be related. This patient is in his 60s, and he reported that, throughout his life, he would only go to the dentist primarily when he had a problem. He also noted that he smoked two packs of cigarettes a day, and that he began smoking around the age of 14 and continued for 30 years. He also reported that he drank beer periodically. Encouraged by his family because he was having breathing problems at work, he discontinued cigarette smoking on his own in the mid-1980's.

In 2000, he developed periodontal disease with severe gingival recession that resulted in a referral to the periodontist. At that time, the periodontist recommended a gingival graft for the management of the receding gums. Mr. OC was also informed that there were unusual white patches in the roof of his mouth, close to the donor graft site. Following patient consent, a biopsy was performed at the time of the periodontal surgery. At the return visit, Mr. OC was

informed that he had lichen planus and that it was a chronic condition caused by stress and aggravated by certain foods and beverages. He understood that there was no treatment to cure this mouth disease. After the follow up visit, he did not return to the periodontist because the grafting procedure did not seem to be successful. To control the symptoms of lichen planus, he learned to avoid certain foods by trial and error. He never mentioned the oral condition to other healthcare providers, and none of them questioned him about having an oral problem. Up to this point he did not recall any healthcare provider, including the dentist, performing an oral cancer examination.

Clinical Disease Progression

The symptoms in the mouth worsened in 2007, when he noticed a red patch covering the side of the tongue, along with the typical white patches in his mouth caused by lichen planus. For more than 6 months, he avoided spicy foods, but eating became more problematic as the pain became constant. At the encouragement of his wife, the patient recalls that he went to see an otolaryngologist, who diagnosed the lesions as leukoplakia and recommended that all of the white and red patches on the tongue be removed by laser treatment. After observing the laser treatment results and the lack of healing on one side of the tongue, a decision was made to refer Mr. OC to a head and neck oncologic surgeon. A wide excision of the lesion on the tongue was performed by the surgeon, who submitted the tissue for microscopic examination. At the follow up appointment, Mr. OC and his wife were informed that a diagnosis of oral squamous cell carcinoma with clear margins had been made.

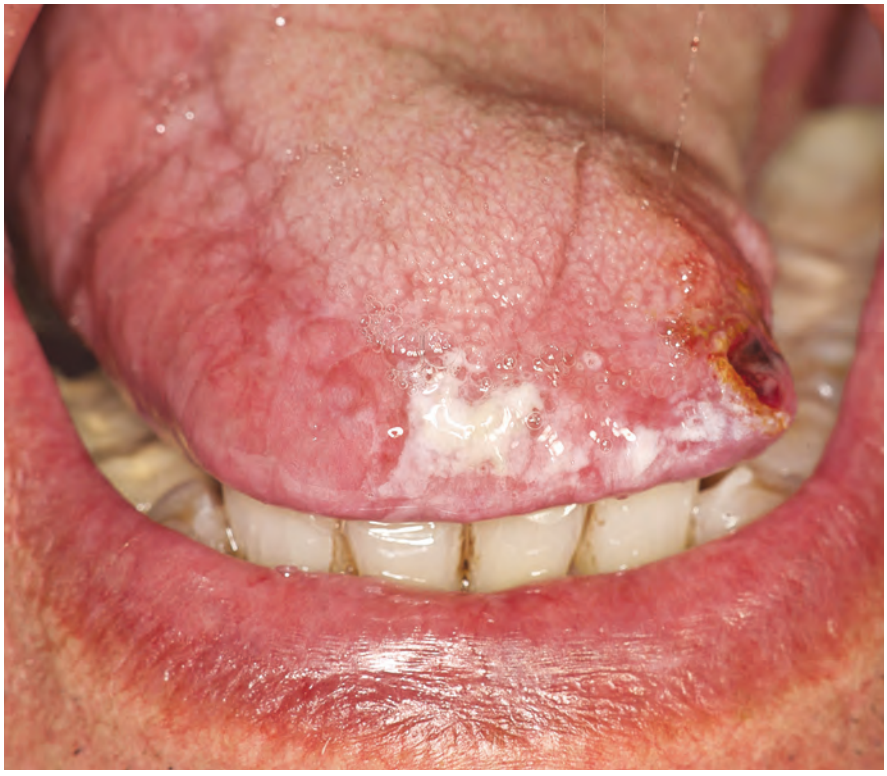

Figure 1. White plaque on the anterior tongue with fresh surgical biopsy site. Note the small size of the tongue and the large depression on the left lateral border where the oral cancer was excised twice.

Approximately 2 years later, the lesion on the tongue recurred and a second surgery was performed, along with removal of the nodes in the neck. After the second surgery, Mr. OC was given the diagnosis of oral squamous cell carcinoma with the good news that the lymph nodes in the neck were free of tumor. He was also informed that the cancer may recur and, if it did, chemoradiotherapy would be the next treatment approach. After the family researched its options, a decision was made to seek experimental chemoprevention at an academic cancer center.

Once arriving at the academic cancer center, a multidisciplinary approach to care was advised that included a head and neck oncologic surgeon, who supervised the entry into an experimental chemoprevention study, and referral to an oral and maxillofacial pathologist for evaluation and management of the lichen planus. The tender oral lesions were widespread and ranged from thick verrucoid-appearing plaques on the tongue (Figure 1) to white lacy striations and plaques with and without focal areas

of ulceration and erythema on the buccal and labial mucosa and attached gingiva (Figure 2). Targeted laser ablation, repeat biopsies, multiple laboratory tests, periodic examinations that include screening with autofluorescence light devices, and appropriate topical and systemic medications have become the standard protocol for managing these two oral diseases. The patient is aware that lichen planus rarely undergoes spontaneous remission and has a reported annual malignant transformation rate of about 0.5 percent (7). Further, he knows the average 5-year survival rate for his type of oral cancer is about 80 percent (8). For these reasons, long-term annual follow up of these oral diseases will be a necessary part of his routine to beat the odds.

What is a Limbo Situation?

We now want to move to a discussion of limbo situations. Capps and Carlin define limbo situations as intermediate and indeterminate states and/or places of neglect, confinement, or oblivion (5). They also offer a framework for identifying and understanding such situations, which they derived from their conversations with people living in limbo as well as from psychological literature (5, 6). They suggest that there are different types of limbo situations, such as limbo situations in early life, relational limbo, work-related limbo, illness-related limbo, and limbo situations involving dislocation and doubt. They suggest that there are different durations of limbo situations — that is, limbo situations can be acute or chronic, and, moreover, some acute limbo situations last longer than others. They suggest that there can be different kinds of distress in limbo situations, such as anxiety and worry or dread and despair, and that there can be different intensities or degrees of any given type of distress in an acute limbo situation. The longer one finds oneself in an acute limbo situation, the more likely it is that one will experience various kinds and higher degrees of distress. It is one thing, for example, to be out of work for a month, but it is quite another to be out of work for 2 years and, because of finances, foreclosing on one's home. This framework, we found, proved to be useful in interpreting our conversation with Mr. OC, as one can observe Mr. OC's kinds and intensities of distress changed when the type of his limbo situation changed.

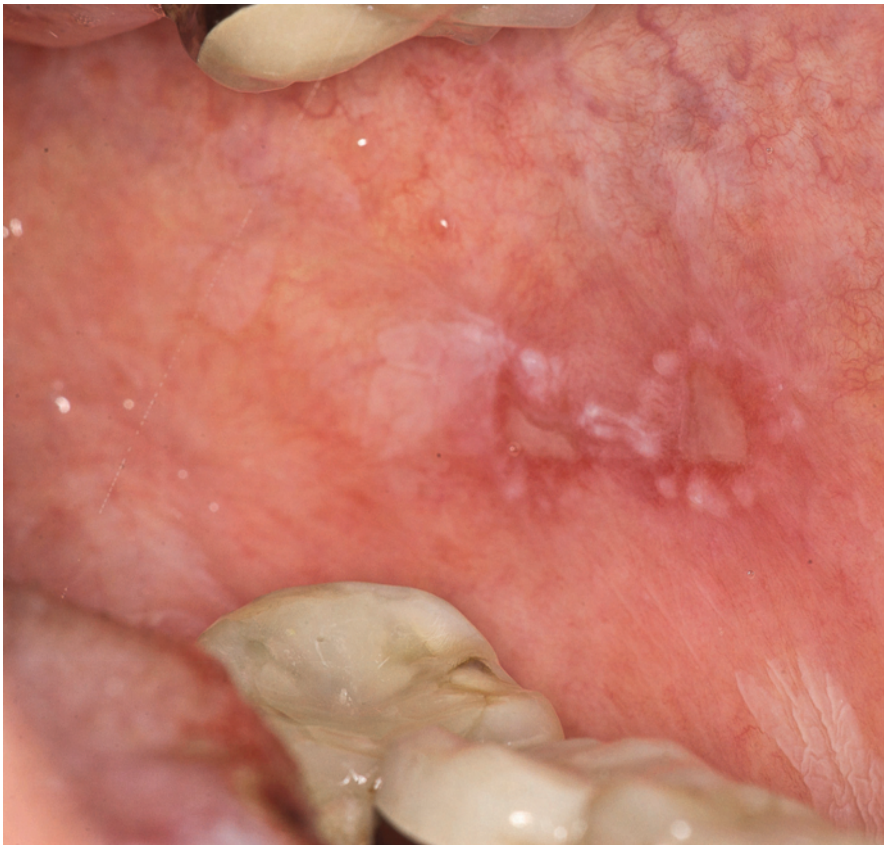

Figure 2. White striations and plaques with superficial areas of ulcerations and erythema of the buccal mucosa.

Oral Lichen Planus as a Limbo Situation: Living with Irritation

A significant confounder to this patient's oral malignancy is the original diagnosis of lichen planus that was made about 7 years prior to the occurrence of oral cancer. Although the patient was aware that he had lichen planus, a diagnosis which was biopsy-confirmed, he did not understand the cause or potential complications of this chronic disease. In part, this may have been due to the fact that he sought treatment for periodontal disease and gingival recession. It was only during the periodontal surgery, which included a palatal grafting procedure, that a biopsy of the adjacent mucosa was excised for evaluation of a white patch. The patient noted that he did not follow up for routine periodontal maintenance because he did not feel that the surgery had been successful.

It is normal for patients who have oral lichen planus to fluctuate between periods of disease exacerbation and remission for years. This, in itself, is a kind of limbo situation. Although many patients with lichen planus control the symptoms by meticulous oral hygiene, monitoring their diets, and the periodic use of topical steroids, there are the inevitable flare-ups that can create a prolonged state of uncertainty along with a loss of control and a compromise in the quality of life. To complicate matters, the drugs most commonly used to control the signs and the symptoms of lichen planus are dermatologic agents that are adapted for oral use. Pharmacists are often unaware of this off-label use of the drug, and so, when they question this application inside the mouth, patients are often confused and unnerved. It is further disconcerting to patients when the drug label clearly states in bold letters, "For external use only — call Poison Control if ingested." Not unexpectedly, some individuals fear the potential complication of long-term topical steroid use as much as the disease itself, thus creating another layer of unease, as patients wonder, "Am I doing more harm than good by using these agents?" (9, 10).

The patient did comment on how lichen planus affected his daily life. He noted that he lived with a chronic state of oral discomfort, and that he coped with his discomfort by avoiding certain foods. In this sense, he lived in a chronic state of confinement. He reported that he did not seek additional care for the lichen planus because he was informed that there was no cure — only that it was aggravated by stress and certain foods. Furthermore, he never mentioned the oral problem to other healthcare providers because he tended to seek care intermittently and for specific reasons—he did not want to bother anyone with an unrelated concern. In terms of Capps and Carlin's framework (5), although he was experiencing an acute limbo situation that lasted for many years, he did not experience significant levels of anxiety because he knew that his condition was not curable and because lichen planus was not life threatening. Oral lichen planus, understood here as a case of illness-related limbo, was characterized more by irritation and frustration than by any other emotions.

When reflecting on his diagnosis of lichen planus, the patient stated that he wished that he would have known more about the disease and that rare cases may undergo malignant transformation. On this detail, we pointed out to the patient that the association of the oral malignancy with this persistent inflammatory disease was controversial, and we also emphasized that it was uncertain if managing the lichen planus would have had any impact on disease progression (7). Both of these facts are all part of the limbo of living with this common oral disorder. In any case, what is striking about this observation from the patient is that, in retrospect, he would have preferred to have had lived with the uncertainty of the possibility that rare cases of lichen planus undergo malignant transformation then than to living with the uncertainty that he lives with now. Why? Because the uncertainty that he lives with now has a tinge of regret: "If I would have acted sooner, could my oral cancer have been prevented?"

An important problem with lichen planus is that it can mask more serious oral diseases because it is red, white, or ulcerated—similar to oral cancer. Although semiannual or annual periodic evaluations are emphasized for early detection of suspicious lesions, a healthcare provider cannot prevent a ma-

lignancy from developing. The healthcare provider faces some uncertainty because of the lack of disease predictability and the overlapping clinical features with more serious diseases, and so healthcare professionals often live in their own kind of limbo, creating, as it were, a kind of double patient-dentist limbo. The uncertainty of healthcare professionals, we suggest, should be openly discussed so that realistic expectations and management approaches are decided jointly. With this particular patient, the persistent oral lesions and constant tenderness allowed him to rationalize that the painful tongue lesions were a part of the lichen planus, which significantly delayed the seeking of care and the diagnosis of the oral cancer.

Oral Cancer as a Limbo Situation: The Decision to Participate in an Experimental Study

We now want to move to a discussion of oral cancer as a limbo situation, the situation in which the patient is currently experiencing. In our conversation with the patient, our initial interest was to find out why he had volunteered to take part in an experimental study at the academic cancer center. We also wanted to view his decision in context. We wanted, in other words, something more than a one sentence answer such as, "Because I want to live," or "Because I want to help other people." We, therefore, asked the patient a series of questions so as to encourage him to tell his story. Much of the conversation focused on the clinical disease progression. At various points during the conversation, we asked the patient how he felt during different stages of the progression of his illness. The most striking part of the interview was when we asked the patient to comment on the worst part of his disease. He did not identify pain as the worst part, and he did not identify the financial hardships, though considerable, as the worst part. The worst part, he said, was "the waiting." This comment from the patient is what led us to use the category of limbo to understand this patient's experience.

When the patient was diagnosed with oral squamous cell carcinoma, he remembers feeling frightened, especially because he was told that there was nothing that could cure his condition. He remembers that he was given several options. One was to do nothing, but this would lead to death. Another was to have surgery. He was reluctant to have surgery, however, because he remembered that his neighbor developed cancer of the neck and that he had multiple surgeries and yet he ended up dying anyway. He did not want to end up like his neighbor. A third option was to have some combination of chemotherapy and radiation, but he was advised that this should only be "a last resort." At first, he elected to do nothing, because he did not want to end up like his neighbor. His wife, however, persuaded him to have surgery. This decision — Which option do I take? — is a kind of limbo situation, and his wife helped him through this one as he elected to have surgery. After he had the surgery, he thought — or hoped — that it was all over, and he felt a sense of relief. But when the cancer came back, he felt a renewed sense of

In contrast to the waiting involved with lichen planus, the waiting involved with oral squamous cell carcinoma produced high levels of dread and anxiety in the patient because his life, not simply his quality of life, was at stake. Surgery, then, became no longer an adequate option for him, because "the waiting" literally became a place of oblivion.

dread, for he recalled the fate of his neighbor. The first surgery, then, provided a sense of closure for him — he was moving from being ill to being well — but, after the cancer returned, it became obvious that he would have to return to limbo after each surgery to see if the cancer would return. It is this waiting for the cancer to return — a cancer that would slowly take away his tongue, that would slowly take away his speaking abilities, and that would slowly take away his life — that proved too much for him to bear. In contrast to the waiting involved with lichen planus, the waiting involved with oral squamous cell carcinoma produced high levels of dread and anxiety in the patient because his life, not simply his quality of life, was at stake. Surgery, then, became no longer an adequate option for him, because "the waiting" literally became a place of oblivion. He needed another way, something other than doing nothing or having surgery, and preferably something other than "the last resort." This other way was enrolling in an experimental study.

Enrolling in an experimental study, the patient told us, gave him a way of being proactive. He was on the offense now — he was no longer just waiting for the cancer to return. When he enrolled in the study, he was troubled by the fact that he could receive a placebo instead of the experimental drug, because this would directly challenge his sense of agency. His reason for enrolling in the study, after all, was to be proactive, but, if he received a placebo, he would be confined back in the limbo of waiting for the cancer to return. We do not know if he is receiving the drug — it is a randomized, double-blind, controlled study — but the patient believes he is receiving the experimental drug because he thinks that he has developed some of the side effects associated with the experimental drug. When he developed these side effects, both he and his wife jumped for joy, because now, he believes, he is no longer just waiting for the cancer to return, but, rather, he is waiting for a cure — waiting for life, not waiting for death. These side effects, whether real or perceived, became an occasion for hope.

Implications for Dental Ethics

In the closing questions of our interview, we asked the patient if he had any advice for other patients. He said, "Don't put it off." By this he meant that, when a person begins to notice something wrong in his or her mouth, they should go to a healthcare professional right away. He said that he was afraid that there might be something wrong, and that this fear prevented him from seeking help. He knew that something was seriously wrong for about 6 months or more before he sought help. This advice from the patient has implications for educational initiatives about both lichen planus and oral cancer. Honest and open discussions about the risk factors, clinical features, management options, prognosis, and the advantages and disadvantages of oral cancer screening devices and adjunctive tests are important so that patients are armed with adequate information to make an informed decision about their health. The patient's advice is well grounded in dental ethics (11).

"I would have liked to have known that my first condition could have led to something cancerous." That is, he would have liked full-disclosure, and, as he put it, no "sugar-coating."

We also asked the patient if he had any advice for health care professionals. He said, "I would have liked to have known that my first condition could have led to something cancerous." That is, he would have liked full-disclosure, and, as he put it, no "sugar-coating." The principle of veracity in the American Dental Association Code of Ethics supports the patient's advice here — he wants to know the truth of his situation so that he can make decisions based on the best available evidence (12). This advice from the patient is also well grounded in dental ethics (13). The patient's advice also suggests the importance of ethics education for healthcare professionals, and that students need to know not only basic knowledge of their profession's codes of ethics, but also, how to apply this knowledge in daily clinical practice. The advice from the patient is straightforward and, as noted, well supported

in dental ethics. Viewing this case report in light of limbo underscores other issues in dental ethics, as well — specifically, ethical issues related to autonomy and patient preferences. A few words about key sources in bioethics are needed to put our reflections in context.

A key document in the founding and establishing the field of bioethics is the Belmont Report, which stresses the importance of autonomy, which literally means "self-rule," and respect for persons, as well as other principles (14). Thomas Beauchamp and James Childress later came to refer to autonomy/respect for persons as "respect for autonomy" (15). The basic approach of Beauchamp and Childress in bioethics came to be called the "principlist approach," which involves weighing and balancing, as well as specifying, the principles of respect for autonomy, beneficence, nonmaleficence, and justice in a given bioethical dilemma (16). Some bioethicists have criticized the principlist approach for being simplistic and mechanistic, leading to a kind of listing of principles related to an ethical dilemma rather than a sophisticated application of the principles (17). This oversimplification of the principlist approach is, perhaps, related to a pedagogical strategy for teaching medical ethics in medical schools, which is sometimes called the "four boxes" (18). The four boxes that students use to analyze an ethical dilemma include medical indications, patient preferences, quality of life, and contextual issues. While Beauchamp and Childress never intended their approach to be reduced to a listing of facts and observations, others have argued that the way to rectify such oversimplification is by turning to story and narrative (15, 19). We support this turn to story and narrative, as intimated by our telling of the patient's story here, as a way of strengthening the principlist approach. Why? This turn invites the application of various tools from the humanities to understand human experience, such as Capps and Carlin's framework for understanding limbo situations, in bioethics (5).

What issues in bioethics does the category of limbo bring to light in this case report? We argue that the framework of limbo provides a deeper understanding of his autonomy as expressed in his preference to participate in an experimental study. In terms of bioethics, what is relevant here is not only that he wants to participate in this study, but also, why he wants to do so, and the category of limbo provides an explanation of why he wants to participate in this experimental study. Mr. OC wants to be proactive rather than reactive and, therefore, to do something other than simply wait because the quality of the waiting in the limbo of oral cancer, in contrast to the limbo of lichen planus, was characterized not by irritation and confinement, but, rather, by anxiety and dread as oblivion lay in the horizon.

Viewing Mr. OC's decision to participate in an experimental study in light of his comments about "the waiting," one might wonder about the relationship between his need to find a way out his illness-related limbo related to oral cancer and his understanding of the nature of the experimental drug. Some bioethicists might be pessimistic about the likelihood that the experimental drug, if the patient is actually receiving it and not a placebo, would add any quantity or quality to his life, and that such studies, some worry, exploit false hope for the sake of science and research (20). These are valid concerns. Perhaps one way to begin to think about them, based on our conversation with this patient, is to weigh the likelihood of harm that will come to the patient on account of the experimental drug against the distress of this patient's experience of living in limbo. For this patient, the side effects are minor and they are an occasion for celebration, symbolizing to him that he — not cancer — is on the offense. Viewing the issue in this way means that the risk-benefit analysis is not only a biomedical matter, but also, a personal and individual matter, and that this analysis is more a matter of art than science, more a matter of reflection than calculation.

Concluding Comments

When one is living in limbo, one needs to find a way to pass the time. Mr. OC continues to work and much, if not all, of his time is spent battling his illness. He has found that he is much closer to his family than before, and that, together, they are fighting oral cancer in ways that, without the study, they could not. Perhaps, in time, he will feel differently. But, for now, this experimental research study offers a ray of hope into the darkness of the limbo of oral cancer.

Practice Points

The lessons learned so far from the experiences of this patient are straightforward and outlined below.

1. It is not uncommon for patients to delay seeking care when they feel that they are experiencing a serious disease. Empathy for the fears of the patient, as well as an honest discussion about the oral problem, is critical for motivating the patient to receive appropriate care.
2. Detailed disclosure about a disease is important so that the patient can understand the full impact of the condition. At times, referral to a more experienced specialist may be necessary to provide the patient with the most current and accurate information.
3. Sometimes patients are not aware that their dentist is evaluating them for oral abnormalities, such as cancer, during a routine examination. For this reason, it is important to inform the patient what the oral examination entails and why it is being performed.
4. Communication styles of patients vary, and reserved conversation should not be interpreted as lack of interest. Furthermore, respect for an authority figure, such as the dentist, may significantly inhibit the asking of life-saving questions, unless the patient is encouraged to do so. The patient in this case report did not want to bother healthcare professionals with his questions about lichen planus.
5. Oral potentially malignant disorders, such as lichen planus, are challenging because of the persistence of the disease, variable malignant transformation rate, unpredictable behavior, and debate over the best treatment approaches. These uncertainties induce not only illness-related limbo for the patient, but also stressful ambiguity for healthcare providers.
6. Not all limbo situations are the same. For this patient, lichen planus produced one kind of limbo experience — one that was relatively free of dread and anxiety — but oral cancer produced

a different kind of limbo experience — one that was characterized by dread and anxiety. The difference between the two situations is on account of the fact that the latter is life-threatening and, therefore, produced higher levels of distress.
7. Enrolling in experimental research protocols may be one way that patients attempt to propel themselves out of illness-related limbo.

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