

# More Than a Sore Mouth: Patients' Experience of Oral Mucositis

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**Purpose/Objectives:** To explore patients' experience of chemotherapy-induced oral mucositis.

**Design:** Interpretive descriptive, phenomenologic.

**Setting:** The cancer center of a metropolitan teaching hospital in South Australia.

**Sample:** A purposive sample of six participants undergoing intensive cytotoxic therapy associated with autologous hematopoietic stem cell transplantation.

**Methods:** Patients were interviewed at different stages of their treatment trajectory and asked to relate their experience of oral mucositis as it developed and resolved.

**Findings:** Participants' reports indicated three distinct phases representing linear time in the course of their mucositis: the preparatory phase, the peak phase, and the persisting phase. Five themes further abstracted were the presence of nurses, therapeutic interventions, manifestations of mucositis, the distress of eating (and not eating), and whether the treatment was worthwhile.

**Conclusions:** Oral mucositis is much more than a sore mouth. The effects of mucositis are widespread and can have a marked effect on patients' psychological well-being.

**Implications for Nursing:** Care centers often focus on pain control through pharmacologic intervention and overlook the effects of other sequelae. Nurses' role in helping patients to cope with mucositis should encompass more than providing pharmacologic pain relief.

## Key Points . . .

- ▶ Patients experiencing chemotherapy-induced oral mucositis have more than just a sore mouth.
- ▶ Oral symptoms have the potential to persist beyond discharge from acute care.
- ▶ Nurses' role in the management of mucositis should encompass more than the provision of analgesia.

the response to treatment. Whenever possible, mucositis should be prevented or, at least, treated to reduce its severity and sequelae (Kowanko, Long, Hodgkinson, & Evans, 1998).

Currently, few interventions are used for the prevention of mucositis, but many treatment options exist. However, a recent systematic review of the literature revealed a lack of research evaluating the effectiveness of treatments currently available (Kowanko et al., 1998). A further search of the literature revealed a corresponding paucity of research investigating the effects of oral mucositis on quality of life. Studies investigating the effects of intensive chemotherapy regimens generally have examined the total picture of side effects experienced, including nausea and vomiting, diarrhea, weight loss, anorexia, alopecia, and fatigue, as well as mucositis. Such research has shown that patients tend to minimize difficulty with side effects as a method of coping and may not

Oral mucositis is a common, debilitating complication of cancer chemotherapy and radiotherapy that occurs in approximately 40% of patients receiving standard dose chemotherapy (Graham, Pecoraro, Ventura, & Meyer, 1993) and in the majority of patients undergoing high-dose chemotherapy, such as that used after bone marrow transplantation (Armstrong, 1994; Zerbe, Parkerson, Ortlieb, & Spitzer, 1992). Oral mucositis occurs as a result of the cytotoxic effects of chemotherapeutic drugs and radiation on the oral mucosa. Mucositis causes severe pain and distress and may limit the tolerability, and therefore effectiveness, of chemotherapy and radiotherapy. Furthermore, patients with damaged oral mucosa and reduced immunity resulting from chemotherapy and radiotherapy are prone to opportunistic infections in the mouth. Mucositis can be so severe that patients' food and fluid intake, gum and dental condition, speech, and self-esteem are reduced, further compromising

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point them out as causing any distress unless questioned directly (Persson, Hallberg, & Ohlsson, 1995). This minimization or denial may result in nurses' lack of awareness of the impact of these side effects. In addition, chart records have shown significant underdocumentation of oral mucositis as a side effect when compared with interview information (Dodd, Facione, Dibble, & MacPhail, 1996).

The purpose of this study was to examine patients' experience with mucositis and, in turn, address the lack of visibility of oral mucositis as a common side effect of chemotherapy. This study sought to determine what an episode of oral mucositis is like and how nurses can assist patients to prepare for and cope with the experience. Exploring patients' thoughts, feelings, and opinions during times of ill health helps to explain the nature of ailments as human conditions. Insight gained from participants enables nurses and other healthcare personnel to better assist patients in dealing with debilitating conditions.

## Literature Review

A review of the recent literature (1995–2000) highlighted the scarcity of literature specific to oral mucositis in areas other than clinical studies evaluating the benefits of different preventive and treatment interventions. Literature specific to oral mucositis in relation to quality of life and the impact on individuals is sparse, particularly following the acute episode. Studies designed to evaluate mucositis pain have been conducted (Donaldson, 1995; McGuire et al., 1998; Mueller, Millheim, Farrington, Brusko, & Wiser, 1995). Cancer-related pain is a multidimensional experience made up of physiologic, sensory, affective, cognitive, behavioral, and sociocultural dimensions. Studies have revealed discrepancies between patients' and nurses' perceptions of symptom occurrence and distress (Tanghe, Evers, & Paridaens, 1998) and that patients often do not express pain because they are afraid of "annoying" nurses (Francke, Garsse, Abu-Saad, & Grypdonck, 1996). Loprinzi et al. (1994) conducted three studies comparing patients' self-reports with nurse and physician assessments of their pain. In each study, caregivers tended to underestimate patients' perceived discomfort. However, congruence improved after each study, indicating that informing caregivers about the results decreased the discrepancy.

A study of patients' experiences of protective isolation following bone marrow transplantation (Gaskill, Henderson, & Fraser, 1997) was significant for its hermeneutic phenomenologic method and implications for nurses' roles in helping patients to cope with their experience. One of the major themes that emerged from the Gaskill et al. study was "striving to take charge." Patients said that knowing that information was available on request was important. Interestingly, although participants wished to stay in control of their situations, they indicated that healthcare professionals did not fully appreciate and understand the experience from their point of view and that this understanding was important to them. The study revealed the importance of nurses' and other healthcare professionals' roles in providing adequate information and caring for and about their patients.

The phenomenon of oral mucositis has a subjective component. The literature shows that pharmacologic treatment regimens for this condition are well articulated, but not evidence based, and that common misperceptions exist among health-

care professionals about what it means for patients to have mucositis. Previous research has not focused exclusively on patients' experiences. Furthermore, the complete episode of oral mucositis has not been investigated from the time before symptoms arise to resolution.

## Methods

The current study was interpretive, informed by phenomenologic discourse. Phenomenology is a philosophical movement as well as a method and offers an approach to nursing research that can be adapted usefully. The authors of this study took a phenomenologic approach because it involved experiential descriptions of particular phenomena and emphasized the meaning of lived experience (van Manen, 1990). The aim of this study was to generate a clearer understanding of patients' experience of mucositis. According to van Manen (1995), phenomenology awakens the experience of human life in a reflective manner that inevitably helps individuals to become more thoughtful and understanding. The task of phenomenologic research and writing is to "construct a possible interpretation of the nature of a certain human experience" (van Manen, 1990, p. 41).

### Setting and Participants

This study was conducted in a specialist cancer center in a metropolitan teaching hospital. All participants were patients undergoing intensive cytotoxic therapy associated with autologous hematopoietic stem cell transplantation. Patients undergoing transplantation were chosen because they were predicted to experience mucositis (Zerbe et al., 1992) and would be returning for outpatient medical care, thus facilitating long-term follow-up. All participants received standard mouth care according to the unit protocol (i.e., regular gentle cleaning and a prophylactic antifungal agent).

The study had a purposive sample of six participants: four women and two men ages 38–63. The participants were consecutively admitted to the hospital to undergo autologous stem cell transplantation for the treatment of various hematologic disorders and were selected because of their potential to be "information rich" cases (Patton, 1990).

Patients were excluded from the study if they were unable to speak and read English or too physically or mentally debilitated to complete informed consent, had an expected survival of less than three months as determined by a primary physician, or declined participation.

### Data Collection

The study was designed to explore the nature of oral mucositis as it developed and resolved. Rather than taking a "snapshot" approach and interviewing patients only once, the researchers chose to interview participants weekly for four weeks and thereafter at week 8 and week 12 or until their symptoms of oral mucositis had resolved. All patients were interviewed prior to the commencement of high-dose chemotherapy and again, as planned, until the peak phase of their mucositis experience. At that point, however, a number of unforeseen problems arose that made adhering to the proposed schedule of interviews difficult. Because of severity of symptoms, three participants refused interviews during the peak phase of their mucositis. At this time they were encouraged to record their perceptions in journals instead. Three

patients died during the period of the study, and some participants had difficulty keeping interview appointments after their discharge from the hospital. As a result, some follow-up interviews were conducted over the telephone.

Nineteen interviews were conducted, audiotaped, and transcribed verbatim. The interviewer made journal entries that recorded images, impressions, and feelings immediately following contact with the participants to preserve as much of the dialogue as possible. Participants also were asked to record their thoughts and feelings in journals. However, the participants made little use of their journals, possibly because when the mucositis was severe, they felt too unwell to make entries. Thus, journal material was not included as data.

In keeping with an in-depth interview technique, interviews were anticipated to last approximately 45 minutes to one hour, but some interviews were shorter, depending on how participants were feeling. Meetings were conducted in patients' hospital rooms when isolation was required or in suitable rooms in the hospital. After discharge, interviews were conducted in venues agreeable to the patients, usually in the outpatient department, and in some cases, over the telephone.

The interviewer was an experienced oncology nurse with a research background who was not involved in providing direct care to the participants. The interviewer encouraged participants to present rich descriptions of mucositis by sensitively prompting them to recount their experiences using well-established phenomenologic interview techniques (van Manen, 1990). Each interview presented an opportunity to delve more deeply and widely into participants' experiences. Eventually, the researcher began to see repetition occurring in the dialogue and, toward the end of the project, was satisfied that the phenomenon of interest had been explored as far as possible within the confines of the study.

The ethics committee of the participating institution approved the study. Ethical issues for consideration were participant anonymity, informed consent, safe storage of data, and participant comfort.

## Data Analysis

Each member of the research team read the interview transcripts several times so that participants' narratives could become known and similarities and dissimilarities in experiences could be uncovered. The principal investigator had extensive experience in phenomenologic research. The team met as a group to identify and discuss themes emerging from the data. As the participants' stories and anecdotes were read, the team sought to answer the questions, "What is going on here?" and "What is the essence of the experience for this participant?" After the preliminary themes and phases had been identified, all were considered further to provide deeper understanding and five additional themes emerged. No technical procedure for validating a phenomenologic account exists; nevertheless, an interpretive study can be judged by a number of factors (Leonard, 1994), including the care with which questions are framed and initial interpretive stance laid out, the method by which data collection is accomplished and documented, and the degree to which the interpretive effort goes beyond publicly available understandings of a problem to reveal new and deeper possibilities for understanding. In the current study, the final interpretation of patients' experiences of mucositis was intended to represent a plausible, understandable, and illuminating account of the phenomenon of mucositis.

## Results

### Sample

The sample was comprised of the following individuals who, for the purposes of this article, are referred to as Alice, Bill, Carla, Derek, Ellen, and Fiona.

- Alice: 38 years old, married, with two young children
- Bill: 41 years old, divorced, with children and a new partner (from whom he has since separated)
- Carla: 63 years old, married, with adult children
- Derek: 45 years old, married, with adult children and one grandchild
- Ellen: 60 years old, married, with adult children
- Fiona: 62 years old, married, with adult children and grandchildren

The results of this study indicate that the participants lived toward a future (although understandably a future with uncertain horizons) and that the passage of mucositis was marked along a linear time trajectory. The passage included three phases: the preparatory, the peak, and the persisting phases. Patients placed themselves in relation to these phases in time and used them for orientation in relation to their transplant treatment. For example, during her first interview, when asked about her mucositis, Alice said, "It seems to be alright at the moment apart from being dry. We'll have to wait and see what happens down the track. . . ." Ellen, at a similar interview, said that her mucositis was "probably progressing" but she was hoping that next week she "might be a different girl." On further analysis, five themes emerged within these phases that were considered to be central to the participants' experience and provided insights with practical implications.

### The Presence of Nurses: "Doing a bit of this and a bit of that"

The participants talked about the role nurses played in their mouth care. Derek said that nurses were more concerned with "the daily routines." The participants overwhelmingly saw the doctor as being responsible for scrutinizing their mouths. About nurses, Bill commented that "they don't actually do anything [in relation to mouth care]." All of the participants said, however, that nurses were there to remind patients to care for their mouths. "They just make sure that you've got your things." Patients also knew that when things got "bad," the nurses would step in. Fiona commented, "If I was unable to [care for my mouth] . . . they would."

Nurses made useful suggestions when things were not going well. They suggested pain relief and alternate forms of mouthwash: "One of the nurses got [an oral agent] for me to try." "One of the nursing staff suggested to just use water, and I found that pretty good relief." An important function for nurses was to provide encouragement and listen to patients' wishes. This made patients feel that they had control, which was important to them. Nurses assisted patients in various ways to ameliorate symptoms when mucositis was at its peak. For example, Derek's tablets were crushed and, when possible, he was given IV medication instead. Alice stated, "On a bad day, the nurses got the [lidocaine] for me to try . . . something they don't normally use." For her, this was "encouraging" and gave her back a feeling of being in control. Fiona talked about her loss of control through mucositis-related diarrhea and spoke of the nurses "giving me tablets to stop [it]." The nurses' major roles were to predict the onset of mucositis in the preparatory

phase and control patients' pain through pharmacologic intervention during the peak phase.

### **Therapeutic Interventions: "I'm glad it's getting better; that's all I can say about it"**

Believing it to be therapeutic, participants generally took their mouth care seriously. Carla carried hers out strictly: "I won't give it away until they tell me I can." Performing mouth care gave Carla "something to do." Most participants talked in terms of a regimen of mouth care—a prescribed range of "lotions and potions" (the names of which they knew well) together with gentle brushing of teeth. The participants themselves largely determined the level of attention given to mouth care. For example, when Fiona was asked if she was doing anything in particular to care for her mouth, she responded, "Well, I'm cleaning [my teeth] at the moment, but I'm only using a very soft baby toothbrush, and I'm using the pink stuff and the [nystatin] to clean three times a day [after every meal]." When Alice was asked the same question, she replied that she was using "[nystatin]. I'm meant to be doing it four times, but I'm actually only doing it once and the [antibiotic mouthwash]—I'm probably using about twice a day." Bill adapted the recommended mouth care to suit his needs: "I was doing regular water rinses but I've stopped that now."

All of the participants were aware of the significance of their platelet counts and did not brush their teeth when the counts were too low. When they were too sick, they did not bother with mouth care because it was "too much effort to get up." Leaving out dental plates and taking pain medication were helpful. The participants all had the expectation that, as time progressed, their mucous membranes would recover. They believed that mucositis was something inevitable that they would have to endure and that it would improve or resolve as soon as their blood counts came up. Referring to her mucositis, Alice said, "It's still sore. Still feels like I've got razor blades there. The morphine is controlling that side of it. . . . [The mucositis] will gradually go; as my platelets go up it will be a lot better." As a result, participants would wait anxiously each day for the results of their blood tests.

### **Manifestations of Mucositis: "I'd say mucositis was the worst thing that happened"**

The participants provided a rich imagery of the impact of mucositis on their lives. That mucositis was not confined to the oral mucosa was obvious. Many of the participants spoke of discomfort in the pharynx, esophagus, and stomach. A "ring" around his Adam's apple caused Derek enormous distress, and Ellen described a feeling as if something was "stuck in her throat." Fiona had a lump in her throat that meant she could not swallow, and, worse still, mucositis affected her "whole gut." This meant that when she could get food down her throat, it led to uncontrollable diarrhea. Differing degrees of mucositis undoubtedly existed; however, although all of the participants experienced the acute phase, not all suffered to the same degree or for the same length of time.

Participants described differing sensations as the mucositis took hold. For some, the onset was abrupt, and for others, initial signs were vague, including a "tingling sensation," a "strange taste," "the beginnings of a few mouth ulcers,"

"vague throatiness," and "mild soreness in the back of the throat." As mucositis advanced and its full impact was felt, participants spoke of distinct periods of misery. The physical experience of mucositis could be explained by all or some of the participants' descriptions (see Figure 1).

Participants longed for the mucositis to be over but soon determined how to make the experience easier and self-managed their symptoms. Alice, for example, only would eat and drink once she had morphine. She also was on total parenteral nutrition at night "to top [her] up." This comforted her because it reduced "the pressure to eat." Patients who received supplemental feeding through a nasogastric tube found this to be a bad experience. Ellen described "having a tube in" as "strange"; Derek had his removed because it was so "unpleasant." Ellen also could not persevere with the tube, and when it was removed, she felt "like a new person."

Before discharge, Carla said that the resolving nature of her mucositis gave her "confidence." For some, however, the mucositis did not end as expected. Oral symptoms persisted well after discharge. For Derek and Fiona, the persistence of their mucositis was unexpected and a source of great unhappiness. When Derek was interviewed five weeks post-transplant in the outpatient setting, he said that he still needed to consider what he ate: "I can eat and swallow, but I can still feel something in this throat part. [I have] no taste and no real appetite." As a result of ongoing oral dryness, Fiona still was using artificial saliva six weeks after her transplant.

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- A heightened and unrelenting awareness of one's mouth and upper gastrointestinal tract
  - A mouth so dry it could be described as "growing oral fur"
  - Living with foul breath
  - A tongue that is "stuck to the roof of the mouth"
  - A tender mouth and a swollen mouth
  - Definite changes in taste
  - A complete loss of appetite
  - Anguish in the belief that eating is necessary for survival, yet not wanting to eat; thus, making oneself eat
  - An inability to swallow, including swallowing saliva, and attempting to "swill things down"
  - Being able to eat only "mushy" baby food
  - Needing to retrain oneself to eat
  - Having to concentrate on the mechanical act of eating, especially swallowing
  - Feeling anxiety at mealtimes that swallowed food would not "go down"
  - Enduring the "pain and irritation" of a nasogastric tube
  - Trying hard not to be sick; being sick
  - Losing familiar tastes and being unable to enjoy small pleasures such as a cup of tea or a good meal
  - Discovering that some things, such as fruit juice, "sear" the throat
  - Having oral and gastric discomfort described as "the burn of caustic soda" and the "slice of razor blades"
  - Having to perform regular mouth care with "horrible" washes
  - Needing to resort to such things as artificial saliva
  - Feeling tired and having to talk with effort
  - Too much talk leading to a "raspy" mouth and throat
  - Becoming socially isolated as a result of the sheer discomfort of mucositis and its effects
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**Figure 1. Patients' Descriptions of the Physical Experience of Mucositis**

## **The Distress of Eating (and Not Eating): “Eating plays a big part in our lives—you do not realize this until you can’t do it”**

For the participants, one of the most frustrating aspects of mucositis was that it made eating so unpalatable. Swallowing was a major problem and appeared to stem from a combination of dry mouth, pain, and constriction in the throat. All of the participants suffered periods of not eating and found this disturbing because they equated eating with recovery. During periods of restricted eating, nutritional intake often was augmented with parenteral or enteral feeding. When able, participants progressed to eating “slippery” food, such as custards, jellies, porridge, and instant soup. Along with the mechanical obstructions associated with eating, distress stemmed from distinct alterations in the perception of taste.

Participants lamented their inability to enjoy life through the simple pleasure of food and drink. Derek ate only because he knew he had to eat. “I don’t taste it, but I know it’s doing me good.” He was eating custard because he wanted to show the hospital staff that he was eating and therefore able to “get out,” but he had no hunger and could not taste the food. Patients saw their throats as governing everything. As Derek said, “That’s the one that makes you not want to eat or talk; you don’t want to do anything.” Alice made a conscious decision not to worry about eating during the peak of her mucositis. She believed it was a phase of the treatment that would pass and she would start to eat again. Yet, when she did start eating again, she described the process as having to “learn all over again,” especially “relearning” how to swallow. Eating, an act that had been ordinary, simple, and taken for granted, suddenly became a problem.

Many participants commented on the hospital food, which they considered unpalatable at the best of times and decidedly less so during the experience of oral mucositis. In addition, Alice said, “Hospitals don’t help because you’ve got to order 24 hours in advance and you don’t know how you’ll feel then.” Ellen felt “guilty” returning uneaten food on her tray.

### **Was the Treatment Worthwhile?: “No pain, no gain”**

In relation to oral mucositis, participants talked about whether they would go through the treatment again having experienced its effects. Alice, who died shortly after her treatment, said that at one stage, she saw “light at the end of the tunnel. . . . If you have to go through it again, you have to go through it again.” Bill saw the emotional and psychological toll on his body as more exacting than anything physical. Interviewed in the hospital, he did not believe his mucositis had been “that bad.” Following discharge, however, he was much more somber about the whole experience. Approaching his 85th day of treatment, the experience was “taking a lot out of him.” Carla believed that the mucositis was the worst part of her whole treatment, yet she felt “lucky” to “get away with what she did.” Carla was discharged but died at week 8. Derek, whose mucositis persisted long after discharge, thought twice about going through it all again.

There’s days when you think you couldn’t ever go through this again and there’s days when you sit and think, well, I’ve got to see my results first. If you have a scan and a bone marrow biopsy and they say you’re all clear, then

down the track you probably would go through it again. Having been though it, I wouldn’t wish it on anyone. This has been harder than I thought. You just have no energy and no life at home. You *can’t* do nothing. Basically, you sit in a chair all day.

Ellen was philosophical and believed that patients could not expect to go through such a treatment and not suffer. “No pain, no gain. . . . You can’t expect to feel 100% all the time.” She likened the experience to childbirth.

They tell you it’s going to be hard but you don’t understand how hard—but once you’ve been through it, you forget about it. If it gives me a couple of years, yes, a week or 10 days in the back blocks isn’t much to put up with, really.

Fiona said that mucositis was part of the treatment and so she “had to put up with it.” She felt she had no choice but to have the treatment and that it certainly was worth it if the results were good. For her, mucositis had just been “part of the treatment.”

In relation to long-term resolution of the oral symptoms at two and a half weeks postdischarge, Bill described his mucositis as “fine” and just “slight tingling sensations.” Carla died at week 8, and Ellen was discharged to the country and could not be contacted. Alice had mucositis up until her discharge at week 4. For the other participants, however, mucositis continued beyond the peak phase. Derek’s mucositis continued well past discharge (week 11) and considerably diminished his quality of life. Fiona was contacted at week 6 and stated that her concerns with eating and drinking probably were worse now than they had been while she was in the hospital. At week 12, she was too unwell to interview.

## **Discussion**

This study revealed that healthcare professionals had prepared patients undergoing intensive cytotoxic therapy associated with hematopoietic stem cell transplantation for the onset of mucositis. The findings suggest that participants expected mucositis and were prepared to see it through, believing it would be unpleasant but short-lived. The study revealed, however, that participants believed that healthcare professionals did not understand the problem fully. The need for accurate printed information about mucositis reinforced with verbal explanation was clear. In this study, although healthcare personnel may have been “in touch” with mucositis at the outset of treatment (i.e., through the provision of patient information), that level of understanding and support may not have been sufficient and certainly was not maintained during the persisting phase of the problem.

Some participants suffered with mucositis more than others. Moreover, because of the large percentage of patients who died during or shortly after their treatment, in some cases, the full effects were not captured. Participants’ views on whether they would repeat the treatment were largely positive. Once the initial inpatient stay was over, the continuing treatment regimen became a problem, along with sheer exhaustion. In addition, for two of the discharged participants, the persisting nature of their mucositis severely detracted from their post-transplant quality of life.

That the participants did not expect nurses to play a large part in their mucositis experience was interesting. Phenomen-

ologists have noted that while living in a sick body, patients quickly learn what feels best for them (van den Berg, 1966). Indeed, all of the participants viewed mouth care as their own responsibility. Nevertheless, when “the going got tough,” nurses were viewed as being there to provide support and offer comfort measures and, in many cases, they did. However, the literature clearly states that symptom management is essential for patients with mucositis (Rhodes, McDaniel, Homan, Johnson, & Madsen, 2000; Yeager, Webster, Crain, Kasow, & McGuire, 2000) and that skilled nursing can play an important role in assisting patients to overcome its effects (Dodd, 1997; Haberman, 1995; Kruijver, Kerkstra, Bensing, & van de Wiel, 2000). The current study indicated that nurses should intervene before the situation becomes difficult.

The importance of food in daily life is discussed in the literature. Studies clearly show that quality of life is significantly compromised for patients who find eating difficult, if not impossible (Bellm, Epstein, Rose-Ped, Martin, & Fuchs, 1999; Meares, 1997). A need exists for thorough nursing assessment and ongoing vigilance during episodes of mucositis. A variety of strategies must be devised and offered to ameliorate the effects of patients’ diminished enjoyment in small pleasures, such as eating and drinking. These strategies should be planned individually in consultation with patients and are well within the purview of nurses. Recent studies have emphasized the need for nurses to recognize the contributions they can make to patients’ nutritional well-being (Kowanko, 1997; Kowanko, Simon, & Wood, 1999).

One of the most interesting results of this study was the potential for oral symptoms to persist and become chronic. This important finding is not evident in the literature on cytotoxic chemotherapy-induced oral mucositis. An underlying assumption in nursing and medical rhetoric is that once ulcerations have healed and patients are swallowing, all is well. Although this study followed patients for a relatively short period of time, none of those interviewed following discharge and at 12 weeks post-transplant had experienced complete resolution of their oral symptoms. Participants were prepared for acute mucositis, but the longer-term problems of altered taste, difficulty swallowing, mouth dryness, and associated loss of appetite were sources of unanticipated distress.

Another phenomenon was the importance of differing sites of mucositis. Although some of the participants did not actually develop mouth ulcerations, all participants complained of severe throat pain. This is validated by studies revealing that mucositis affects the mouth, throat, and esophagus (Bellm et al., 1999). Furthermore, participants did not separate mouth ulcers from taste changes, mouth dryness, esophageal discomfort, or dysphagia. Congruent with the findings from this study, research has shown that dysfunctional orality is the single most debilitating side

effect of chemotherapy (Bellm et al.; Dikken & Sitzia, 1998; Sitzia & Wood, 1998). The current study’s researchers contend that healthcare providers should give this side effect greater emphasis in patient care.

## Implications for Nursing Practice

Interpretive studies do not profess to reveal ultimate truths; rather, they seek to transform lives through illumination. Interpretive descriptions come out of and are validated by experience (van Manen, 1990). The current interpretive account of lived experiences provides new insights into the condition of mucositis, which, in turn, should open up new possibilities for engaging this very real problem and precipitating further research. Research should include quality-of-life measurements in patients with persisting oral symptoms following mucositis, more extensive studies to determine the long-term impact of mucositis, and experimental studies to explore the effects of specially designed nursing interventions aimed at reducing the effects of oral mucositis.

Some findings from this study already were known. For example, participants’ relative lack of emphasis on pain indicated that pain appears to be well understood and attempts to control it through medication are carried out rigorously. However, problems associated with the combination of loss of appetite and taste, mouth dryness, and inability to eat appear not well recognized. Although the participants believed that they were prepared for the onset of mucositis, in reality, they only were prepared for its physical effects. The psychological sequelae stemming from those physical manifestations (e.g., not eating in the short- and long-term) clearly played a large part in patients’ well-being. The social and emotional aspects associated with mucositis need to be acknowledged and interventions should be planned, especially for patients with persisting oral symptoms. Interventions should include greater focus on the mealtime experience and the pleasures of eating and drinking and involve increased psychosocial support and follow-up to ascertain resolution of mucositis. In cases of persisting oral symptoms, extra support and advice should be provided via outpatient visits and home contact.

Oral mucositis is more than just a sore mouth. Informed and concerned nursing care focused on ameliorating the effects of mucositis can do much to improve the quality of life for patients experiencing mucositis.

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## For more information . . .

- eMedicine: Chemotherapy-Induced Oral Mucositis  
[www.emedicine.com/derm/byname/chemotherapy-induced-oral-mucositis.htm](http://www.emedicine.com/derm/byname/chemotherapy-induced-oral-mucositis.htm)
- The Joanna Briggs Institute Best Practice:  
Oral Mucositis in Cancer Patients  
[www.joannabriggs.edu.au/bp5.html](http://www.joannabriggs.edu.au/bp5.html)
- University of California-Los Angeles School of Dentistry:  
Oral Complications During Cancer Treatment  
[www.dent.ucla.edu/pic/members/cancer/p1.html](http://www.dent.ucla.edu/pic/members/cancer/p1.html)

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