More Than a Sore Mouth: Patients’ Experience of Oral Mucositis

Sally Borbasi, RN, MA, PhD, Kate Cameron, RN, Onc Cert, MNSc, PhD(c), Bev Quested, RN, Onc Cert, MNSc, PhD(c), Ian Olver, MD, PhD, Bik To, MD, and David Evans, RN, MNS

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

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: Patients’ 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.

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 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...