5 themes described the experiences of patients with chemotherapy induced oral mucositis

Borbasi S, Cameron K, Qvested B, et al. *More than a sore mouth: patients' experience of oral mucositis. Oncol Nurs Forum* 2002;29:1051-7.

QUESTION: In patients who are receiving intensive cytotoxic treatment associated with autologous haematopoietic stem cell transplantation, what are their experiences with mucositis?

Design

Interpretive descriptive, phenomenological study.

Setting

A metropolitan teaching hospital in South Australia.

Patients

6 patients (4 women and 2 men, age range 38-63 y) who were receiving autologous stem cell transplantation for treatment of various haematological disorders. Exclusion criteria included inability to speak or read English and expected survival of < 3 months.

Methods

Patients participated in weekly indepth interviews of approximately 45 minutes to 1 hour for 4 weeks and thereafter at week 8 and week 12 or until their symptoms of oral mucositis had resolved. 19 interviews were done, audiotaped, and transcribed verbatim. The research team identified and discussed themes emerging from the data.

Main findings

Patients lived toward a future with uncertain horizons, and the passage of mucositis was marked along a linear time trajectory with 3 phases (preparatory, peak, and persisting). Patients placed themselves in relation to these phases and used them for orientation in relation to their transplant treatment. On further analysis, 5 themes emerged within these phases that were considered to be central to patients' experiences and provided insights with practical implications. (1) *The presence of nurses.* All patients said that nurses reminded them to care for their mouths. Nurses also made useful suggestions when things were not going well, such as suggesting pain relief and alternate forms of mouthwashes. An important function of nurses was to provide encouragement and listen to patients' wishes, which helped patients feel they were in control. (2) *Therapeutic interventions.* Believing it to be therapeutic, patients took their mouth care seriously and determined the level of attention given to it. They did not brush their teeth when platelet counts were too low or when they were too sick. Leaving out dental plates and taking pain medication were helpful. (3) *Manifestations of mucositis.* Discomfort resulting from mucositis extended beyond the oral mucosa to the pharynx, oesophagus, and stomach. Examples of discomfort included "a ring around the Adam's apple", "something stuck in the throat", and uncontrollable diarrhoea. All patients experienced the acute phase, but the degree and length of time differed. (4) *The distress of eating (and not eating).* One of the most frustrating aspects of mucositis was that it made eating unpalatable. Swallowing was a major problem and appeared to stem from a combination of dry mouth, pain, and constriction of the throat. All patients had periods of not eating and found this disturbing because they equated eating with recovery. Distress also related to distinct alterations in the perception of taste. (5) *Was*

the treatment worthwhile? In relation to oral mucositis, patients talked about whether they would go through the treatment again having experienced its effects.

Conclusion

Patients with chemotherapy induced oral mucositis reflected on the role of nurses, took mouth care seriously, had variations in manifestations of mucositis, had difficulty with eating, and wondered whether treatment was worthwhile.

COMMENTARY

Cancer treatments often result in oral complications such as mucositis, but conflicting literature exists about best nursing practice for such complications.¹ Furthermore, little is known about how patients experience mucositis and how it affects their quality of life, especially over a longer period.

Borbasi *et al* chose patients who were having intensive cytotoxic treatment associated with autologous haematopoietic stem cell transplantation and therefore reflect a patient group expected to experience severe mucositis. Oral problems are known to develop 2-3 times more often in patients with haematological malignancies than in patients with solid tumours.¹ A study by McGuire *et al* showed that 89% of 47 patients who received bone marrow transplantation developed mucositis,² which was resolved by 21 days after transplantation. They found that, on average, mucositis began 3 days after transplantation, lasted 9.5 days, and was resolved in 12.6 days.

In light of these earlier findings, the study by Borbasi *et al* is particularly interesting because patients did not have complete resolution of oral problems when interviewed after discharge and at 12 weeks after transplantation. Inability to eat, mouth dryness, and loss of appetite and taste were still present. Whereas the 2 patients with distress 12 weeks after transplantation were prepared for acute mucositis, they were not prepared for long term oral symptoms.

Several interesting questions are generated by this study. For example, interview data from patients might be combined with observational data to better understand the relations between physiological symptoms and experiences of distress. Specifically, does distress remain even after ulcerations have healed and the patient can swallow without difficulty? It would also be interesting to confirm the phenomenological data from the 6 patients with long term problems in a broader sample that included other patient groups receiving chemotherapy.

The study findings highlight the need for nurses to prepare patients for the physical and psychological effects of mucositis, such as the distress of not eating. As well, there is a clear need for nurses to identify and implement interventions that work for patients with mucositis.

Britt-Marie Bernhardson, RN, MA
Clinical Oncology Nurse Consultant
Huddinge University Hospital
Stockholm, Sweden

- 1 Miller M, Kearney N. Oral care for patients with cancer: a review of the literature. *Cancer Nurs* 2001;24:241-54.
- 2 McGuire D, Altomonte V, Peterson D, *et al*. Patterns of mucositis and pain in patients receiving preparative chemotherapy and bone marrow transplantation. *Oncol Nurs Forum* 1993;20:1493-502.

Source of funding:
no external funding.

For correspondence:
Dr S Borbasi, School of
Nursing and
Midwifery, Flinders
University, Adelaide,
Australia.
Sally.Borbasi@
flinders.edu.au