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A survey of National Cancer Institute-designated comprehensive cancer centers' oral health supportive care practices and resources in the USA

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Abstract *Background:* The oral complications and morbidity resulting from overall cancer therapy utilizing radiation, chemotherapy, and/or stem cell transplantation can have significant impact on a patient's health, quality of life, cost of care, and cancer management. There has been minimal health services research focusing on the status of medically necessary, oral supportive services at US cancer centers. *Methods:* A pre-tested, survey questionnaire was distributed to the directors of National Cancer Institute (NCI)-designated comprehensive cancer centers to assess each institution's resource availability and clinical practices, as it relates to the prevention and management of oral complications during cancer treatment. *Results:* Sixteen of the 39 comprehensive cancer centers responded to the survey. Of the respondents, 56% of the centers did not have a dental department. The sites of delivery of oral supportive care services range from the provision of in-house dental care to community-based, private practice sites. No standard protocols were in place for either oral preventive care or for supportive services for oral complications during or after cancer therapy. Fifty percent of the responding comprehensive cancer centers reported orally focused research and/or clinical trial activities. *Conclusions:* Comprehensive cancer care must include an oral care component, particularly for those cancer patients who are at high risk for oral complications. This requires a functional team of oral care providers collaborating closely within the oncology team. Considering the number of cancer patients receiving aggressive oncologic treatment that may result in oral toxicity, the impact of oral conditions on a compromised host, and the potential lack of appropriate resources and healthcare personnel to manage these complications, future research efforts are needed to identify the strengths and weaknesses of present oral supportive care delivery systems at both NCI-designated cancer centers and community-based oncology practices.

Keywords Oral/dental care · Oncology · Comprehensive cancer centers

Introduction

The National Cancer Institute (NCI) is the US federal government's leading agency for cancer research and training. The NCI designates cancer centers into one of three categories: comprehensive cancer centers, clinical cancer centers, and cancer centers. A cancer center's designation as comprehensive, the most prestigious designation, is based upon the center's ability to conduct programs in three areas of research which includes basic,

clinical and cancer control research, as well as programs in community outreach and education. Despite the rigorous peer review that each NCI-designated comprehensive cancer center must undergo, there are no defined guidelines that centers follow with respect to the prevention and management of debilitating oral and dental complications associated with cancer care. These complications include oral mucositis, which may limit or prevent oral nutrition and oral intake of medications, hyposalivation, increased risk of local and systemic infection, dental caries, dysphagia, and osteonecrosis and orofacial function. These complications have the potential to prolong or compromise cancer treatment, require increased use of medical resources, increase the cost of care, and decrease the overall quality of life of the patient [1].

The goal of this survey was to determine the available resources and clinical practices at US NCI-designated comprehensive cancer centers with regard to medically necessary dental assessment and care. The survey instrument was designed to:

- Ascertain the scope of overall cancer treatment modalities at the center;
- Ascertain the availability of orally/dentally related treatment modalities;
- Identify the delivery site(s) of cancer-necessitated dental services (i.e., cancer center dental department, school of dental medicine, community-based dental providers, etc.);
- Explore the circumstances in which an oral/dental referral is sought;
- Determine which cancer center staff members provide oral care instructions to their at-risk patients;
- Determine the institution's level of oral/dental research and clinical trial activities.

Materials and methods

A questionnaire was developed and pre-tested at two hospitals and was utilized in a previous survey of cancer centers [1]. Institutional review board approval was obtained. (UIC research protocol no. 2003-0373). The contact numbers of the directors of the 39 NCI-designated comprehensive cancer centers (as of July 2003) were obtained from the National Cancer Institute website. The director of each cancer center was contacted to approve and then distribute the survey to personnel who might best respond to the questionnaire. This initial contact was made via telephone and upon the approval of the director; the pre-tested survey instrument was faxed, mailed, or e-mailed to the institution. The cancer centers had an option to abstain from participating in the survey and to remain anonymous. Two follow-up contacts were made to non-responding centers at 4-week intervals. The data from the returned questionnaire was entered on Microsoft Excel (Microsoft Corporation, Seattle, WA) software and analyzed.

Results

Sixteen of the 39 comprehensive cancer centers (41%) responded with completed surveys. Eight centers declined to participate in the study, whereas the remaining 15 centers did not respond to the initial and follow-up contacts. The results are summarized in Table 1.

All of the responding centers provide treatment for head and neck cancer. Radiation therapy treatment was available in all responding cancer centers. Radiation therapy was provided to more than 2,300 patients for head and neck cancers. All the centers have both inpatient and outpatient chemotherapy treatment available for their patients. Hematopoietic stem cell transplants (HSCT) were performed in 14 of the responding centers. The replies recorded a total of 190 matched, unrelated donor transplants, 370 allogeneic transplants, 517 autologous transplants, and 388 peripheral stem cell transplants in the prior year. The total number of transplants reported by these centers (1,465) represents the majority of transplants conducted in the US annually.

Dental services are available at 15 institutions. Four of these centers have reported an integrated dental department, and six have identified dental consultants. Nine centers work interface with an associated hospital dental service, and six of the centers are associated with a dental school.

Dental examinations/consultations were reported to be provided to all patients before receiving head/neck radiotherapy at ten centers (62.5%). Seven centers (43.75%) provided oral/dental assessments only for those patients with oral complaints or identified pathology. There were no definite oral care protocols in place at seven centers (43.5%) for patients with identified oral pathology prior to radiation therapy. Of patients receiving chemotherapeutic interventions, three centers provided oral assessment for all of these patients (18.75%), and ten centers (62.5%) reported requesting dental referrals for those with oral complaints or identified pathology. Patients receiving HSCT were examined routinely before treatment at five centers (31.25%), and eight centers reported requesting dental referrals for those with oral complaints or identified pathology (50%). No definitive protocol was in place at two centers (12.5%).

Preventive oral care instructions were provided to patients before treatment for head and neck cancer in seven centers (43.75%). Four of the centers did not have a definite protocol in place. The oral/dental care instructions are provided at the majority of the centers by the dental departments or dental consultants (62.5%). The patients' physicians and nurses were reported to provide these instructions in several centers.

None of the centers required oral care consultation for all of its patients admitted for inpatient cancer treatment. Nine centers (56.25%) provided dental care for treatment-related sequelae to all of their patients, and thirteen (81.25%)

Table 1 Summary of responses to survey of oral health care services and resources in comprehensive cancer centers

Questions	Yes (%)	No (%)	No definite protocol (%)	Not available (%)
1. Radiation therapy	100	0		
2. Inpatient chemotherapy	100	0		
3. Outpatient chemotherapy	100	0		
4. Hematopoietic cell transplant (HCT)	87.5	6.25		6.25
5. Are dental service available and select a type	93.75	6.25		
a. Cancer center dental department	25	56.25		18.75
b. Cancer center dental consultants	37.5	31.25		31.25
c. Associated hospital dental service	56.25	18.75		25
d. Dental school	37.5	62.5		
e. Veteran's Affairs dental service	31.25	25		43.75
6. Types of services provided at different cancer centers				
a. Pre-treatment oral exam before irradiation of the head and neck cancer				
i. All patients	62.5	12.5	18.75	6.25
ii. Patients with oral complaints or pathology	43.75	0	43.75	12.5
b. Pre-treatment oral exam before chemotherapy				
i. All patients	18.75	50	18.75	12.5
ii. Patients with oral complaints or pathology	62.5	6.25	12.5	18.75
c. Pre-treatment oral exam before HCT				
i. All patients	31.25	43.75	12.5	12.5
ii. Patients with oral complaints or pathology	50	25	12.5	12.5
d. Preventive oral care instruction given to patients				
i. Before treatment for head and neck cancer	43.75	18.75	25	12.5
ii. Before treatment for inpatient chemotherapy	31.25	18.75	31.25	18.75
iii. Before treatment for outpatient chemotherapy	37.5	18.75	25	18.75
iv. Before patient receiving HCT	37.5	18.75	18.75	25
e. Who provides the instruction for oral/ dental care?				
i. Physicians	25			
ii. Nurses	18.75			
iii. Dental department/dental consultant	62.5			
f. Are oral care consultations provided to every inpatient?	0	68.75	6.25	25
g. Is dental care for cancer treatment-related sequelae provided?				
i. All patients	56.25	12.5	25	6.25
ii. Patients with oral complaints/ pathology	81.25	0	12.5	6.25
h. When oral pathology is identified, how are these problems managed?				
i. Cancer center medical/nursing staff	31.25	25		43.75
ii. Cancer center dental department	62.5	12.5		25
iii. Hospital-based dental service	50	12.5		37.5
iv. Veterans' Affairs Medical Center dental service	18.75	37.5		43.75
v. School of Dental Medicine	25	37.5		37.5
vi. Private community-based dental provider	43.75	25		31.25
vii. Community-based dental provider other than private dental provider	25	37.5		37.5
7. Dental facilities at your cancer center				
a. Onsite administrative office space	75	6.25		18.75
b. Dental radiology facilities	75	6.25		18.75
c. Sterilization facilities with dental clinic	50	25		25
d. Operating room privileges	68.75	6.25		25
e. Dental care facilities for emergency purposes	68.75	12.5		18.75
f. On-ward supportive care for cancer patients	56.25	25		18.75
g. "End of life" palliative oral care services	31.25	37.5		31.25
8. Is the dental department involved in research activities and/or clinical trials?	50	31.25		18.75

provided dental care to patients with oral complaints or pathology as a result of cancer treatment. Five respondents (31.25%) indicated that treatment-related oral/dental complications were managed by the cancer center's medical and nursing staff. Such patients were referred to cancer center dental departments in ten centers (62.5%). Four of the centers reported that complications were managed by community-based dental providers (25%) who were not the "dentist of record" for the individual patients. Seven centers (43.5%) referred the patients to their own dental providers.

Twelve centers (75%) reported fully equipped dental treatment facilities with administrative space. The same number of centers have dental radiology facilities. Dedicated sterilization facilities within the dental clinic were available in eight centers (50%). Eleven of the centers reported regularly scheduled operating room time allocation for oral/dental treatment (68.75%). Dental emergency services were available in 11 centers (68.75%). Nine of the centers (56.25%) provided on-ward supportive oral treatment to cancer patients while five (31.25%) supported 'end of life' palliative oral care services. Dental departments in eight of the centers were involved in research activities and/or clinical trials (50%).

Discussion

The oral complications arising from myelosuppressive chemotherapy, chemotherapy for epithelial malignancies, HSCT treatment, and radiation therapy (with or without chemotherapy) for head and neck cancer range from oral mucositis, saliva and taste changes to increased risks of local/systemic infection and dental disease. Oro-pharyngeal mucositis often requires opioid analgesics for pain management and may lead to the need for tube/ parenteral feeding, hospitalization, and in severe cases, may compromise the ability to deliver planned cancer therapy. Oral mucositis has been reported as the most distressing of all complications of treatment in head and neck cancer therapy and in HSCT patients [2–4]. Increased cost of care has been associated with acute complications of therapy [5, 6]. Chronic complications may follow such as pain, xerostomia, taste changes, increased risk of infection, dental caries and osteonecrosis of the jaw. After cancer therapy, future dental treatment may be compromised due to local oral changes or a compromised systemic status of the patient.

Current cancer research supports the use of increasingly intensified therapies in order to improve cure rates by utilizing combined chemotherapy and radiotherapy protocols in head and neck cancer and by utilizing "dose-dense" chemotherapy in other malignant diseases. These interventions have increased the frequency, severity, and duration of oral complications, which result in an increasing need for oral care in these patients [7–14].

The importance of oral care as an indispensable part of overall health care is being increasingly recognized [15]. A 1989 National Institutes of Health Consensus Development Conference on 'Oral Complications of Cancer Therapies' recommended oral care assessment and treatment for patients anticipating cancer care. The conference also reviewed the "state of the art" of those prevention and management protocols targeting oral complications commonly identified in patients receiving cancer care [16]. The Surgeon General's Report has recommended including an oral examination as a component of a general medical examination and the referral of patients to dental health practitioners for primary and secondary preventive care before medical or surgical treatments that might damage oral tissues (i.e., cancer chemotherapy or radiation to the head and neck) [17]. The incidence of osteonecrosis has been demonstrated to be reduced in patients who have received comprehensive oral/dental assessment and management before radiation [18].

A limited number of studies have assessed the incidence and progression of oral complications associated with outpatient cancer therapy [19, 20]. However, when examined as end points in studies rather than listed as adverse events, oral/dental complications have been more common than anticipated. Ongoing research to study the potential benefits of a comprehensive intervention targeting medically necessary oral assessment and the dental management of cancer patients is warranted.

Dental intervention is considered an integral element of the overall cancer management paradigm for those patients at risk for oral complications. An interdisciplinary health care team approach has been recognized as the best model for the delivery of this specialized care. The outcome is enhanced when there is: (1) an understanding of the interrelationship between the oral and medical conditions; (2) good interdisciplinary communication through integrated record keeping; and (3) optimal service provision facilitated by the utilization of evidence-based guidelines [8].

This survey has demonstrated that among the responding comprehensive cancer centers, the majority have the capacity to provide radiation therapy, inpatient and outpatient chemotherapy, and HSCT to their patients receiving cancer care. While a recommendation was adopted at the NCI Consensus Conference stating that cancer centers have a dental department [16], 56% of the responding comprehensive cancer centers did not have one. The dental care programs for patients receiving chemotherapy and HSCT were less established compared to those targeting patients receiving radiotherapy. For those cancer patients receiving HSCT, only 44% received oral examinations before treatment, and only 50% of patients having pre-existing oral complaints received oral examinations. These clinical management practices exist despite the known risk of the development of morbidity and risk of mortality due to infection from oral sources during cancer therapy and particularly in myelosuppressed patients if oral disease is

not managed before cancer treatment. The delivery of oral supportive care services ranges from the provision of in-house care to community-based sites. Eleven centers reported the availability of emergency dental services, but just over one half provided necessary dental care to all of their at-risk patients during their cancer treatment. Over 40% of comprehensive cancer centers reported dental evaluation at the patient's prior general practice, community-based dental provider. This raises concern of the level of training and experience of these providers in assessing and managing cancer patients. The best management practices require (1) knowledge of the primary disease and its anticipated cancer therapy and (2) appropriate communication with the oncology.

The results of the current survey and other supporting results suggest that there may be a significant gap in oral care provisions, which may well affect overall cancer treatment outcomes as well as compromises the quality of life of those patients receiving cancer care.

Of the 16 reporting centers, only 50% reported activities in research. Oral supportive care protocols are not similar amongst centers. A pretreatment oral assessment is a standard for all patients in only two thirds of head and neck cancer patients before radiation therapy, one third of patients before HCT, and one fifth of patients who receive cancer therapy. Preventive oral care instructions are provided to approximately one third of patients who receive chemotherapy or HCT and to less than one half of head and neck cancer patients. In addition, only 16 of the 39 comprehensive cancer centers responded to the survey questionnaire. This, in itself, may be a reflection of the limited clinical attention upon oral supportive care at comprehensive cancer centers. The finding that the majority of US-provided HSCT transplants were included in responses to this questionnaire suggests that centers with active dental programs responded to the survey. It is likely that those non-responding centers have less awareness and, possibly, less institutional support for medically necessary oral/dental care. Thus, these survey results may represent an optimistic view of the current status of oral/dental supportive services at NCI-designated comprehensive cancer centers. As evidence-based guidelines supporting the need for medically necessary oral care are developed, a further goal should be to establish capabilities integrated into cancer center programs in order to apply guidelines in patient care.

A similar survey evaluating oral/dental supportive care at provincial cancer centers in Canada obtained a much higher response rate of 83%. However, this again may represent a "best-case scenario" due to the numbers of non-responding centers.

The design and administration of a comprehensive survey instrument, which will render in-depth data regarding available dental resources and clinical practices and provider training needs at NCI-designated comprehensive cancer centers, as well as potentially eliciting a higher study response rate is necessary. Such a study may lead to the enhancement of policy guidelines targeting at-risk oncology patients in need of medically necessary, evidenced-based oral supportive care.

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