Fast Fact and Concept #033: Ventilator Withdrawal Protocol (Part I)

Author(s): von Gunten, Charles; Weissman, David E

Note: This is Part I of a three-part series; Part II will review use of sedating medication for ventilator withdrawal and Part III will review information for families.

Once it is decided that further aggressive medical care is incapable of meeting the desired goals of care for a ventilator-dependent patient, discussing ventilator withdrawal to allow death is appropriate (see Fast Fact #16). Such a decision is never easy for family members, doctors, nurses, and other critical care staff. All members of the care team should be involved and appraised of the decision-making process and have the opportunity to discuss the plan of care.

Options for Ventilator Withdrawal. Two methods have been described: Immediate extubation and terminal weaning. The clinician's and patient's comfort, and the family's perceptions, should influence the choice. In immediate extubation, the endotracheal tube is removed after appropriate suctioning. Humidified air or oxygen is given to prevent the airway from drying. This is the preferred approach to relieve discomfort if the patient is conscious, the volume of secretions is low, and the airway is unlikely to be compromised after extubation. In terminal weaning, the ventilator rate, positive end-expiratory pressure (PEEP), and oxygen levels are decreased while the endotracheal tube is left in place. Terminal weaning may be carried out over a period of as little as 30 to 60 minutes or longer (see ref. 2. for protocol). If the patient survives and it is decided to leave the endotracheal tube in place, a Briggs T-piece can be placed.

Prior to Immediate Ventilator Withdrawal
1. Encourage family to make arrangements for special music or rituals that may be important to them. If the patient is a child, ask parents if they would like to hold the child as he or she dies. Make arrangements for young siblings to have their own support if they are to be present. (See Part III of this series for additional information for families)
3. The physician should personally supervise that all monitors and alarms in the room are turned off. Ensure that staff is assigned to override alarms that
cannot be turned off if they are triggered.
4. Remove any restraints. Remove unnecessary medical paraphernalia (e.g. NG tube, venous compression device).
5. Turn off blood pressure support medications, paralytic medication and discontinue other life-sustaining treatments (e.g. artificial nutrition/hydration, antibiotics, dialysis). Note: some families have difficulty accepting discontinuation of hydration/nutrition-these can be left in place if desired.
6. Maintain intravenous access for administration of palliative medications.
7. Clear a space for family access to the bedside Invite the family into the room. If the patient is an infant or young child, offer to have the parent hold the child.
8. Establish adequate symptom control prior to extubation (See Part II in this series).
9. Have a syringe of a sedating medication at the beside (midazolam, lorazepam) to use in case distressing tachypnea or other symptoms.

At the time of ventilator withdrawal
1. Once you are sure the patient is comfortable, set the FiO2 to .21; observe for signs of respiratory distress; adjust medication as needed to relieve distress before proceeding further.
2. If the patient appears comfortable, prepare to remove the endotracheal tube; try a few moments of "no assist" before the endotracheal tube is removed.
3. A nurse should be stationed at the opposite side of the bed with a washcloth and oral suction catheter.
4. When ready to proceed, deflate the endotracheal (ET) tube cuff. If possible, someone should be assigned to silence, turn off the ventilator, and move it out of the way. Once the cuff is deflated, remove the ET tube under a clean towel which collects most of the secretions and keep the ET tube covered with the towel. If oropharyngeal secretions are excessive, suction them away.
5. The family and the nurse should have tissues for extra secretions, and for tears. The family should be encouraged to hold the patient’s hand and provide assurances to their loved one.
6. Be prepared to spend additional time with the family discussing questions concerns. After death occurs, encourage the family to spend as much time at the bedside as they require; provide acute grief support and follow-up bereavement support.

Reference: Adapted from: Emanuel, LL, von Gunten, CF, Ferris, FF (eds.).


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Non-Physician:

ACGME Competencies: Medical Knowledge, Patient Care
Keyword(s): ICU
Specific Disease and Organ System Category(s): ICU
Fast Fact and Concept #034: Symptom Control for Ventilator Withdrawal in the Dying Patient (Part II)

Author(s): Charles Von Gunten; David E. Weissman
Note: This is Part II of a three-part series; Part I reviewed a protocol for removing the ventilator (FF #33), Part III (FF #35) will review information for families.

The most common symptoms related to ventilator withdrawal are breathlessness and anxiety. Opioids and benzodiazepines are the primary medications used to provide comfort, typically requiring doses that cause sedation, to achieve good symptom control. Concerns about unintended secondary effects, such as shortened life, are exaggerated, particularly if established dosing guidelines are followed (see Fast Fact #8). There is no medical, ethical or legal justification for withholding sedating medication, when death following ventilator withdrawal is the expected goal, out of fear of hastening death. However, increasing doses beyond the levels needed to achieve comfort/sedation, with the intention of hastening death, is euthanasia and is not acceptable/legal medical practice.

Sedation should be provided to all patients, even those who are comatose. The dose needed to control symptoms will depends to some degree on the neurological status of the patient and the amount of similar medication used up to the time of extubation. Patients who are awake at the time of extubation or in whom significant amounts of opioids and benzodiazepines have been used previously, will require greater dosages or change to a barbiturate to achieve symptom control. Note: in all cases, a senior-level physician should remain at the bedside prior to and immediately following extubation until adequate symptom control is assured.

Medication Protocol
1. Discontinue paralytics; Do not use paralytic agents for ventilator withdrawal.
2. Before ventilator withdrawal: Administer a bolus dose of morphine 2-10 mg IV and start a continuous morphine infusion at 50% of the bolus dose/h. Also, administer 1 to 2 mg of midazolam IV (or Lorazepam), and begin a midazolam infusion at 1 mg/h. Note: Sedation should also be administered to the comatose patient. For children, obtain dosing advice from a pharmacist or pediatric intensivist.
3. Titrate these drugs to minimize anxiety and achieve the desired state of
comfort and sedation prior to extubation.
4. Have additional medication drawn up and ready to administer at the bedside so it can be rapidly administered, if needed to provide symptom relief.

5. After ventilator withdrawal: If distress ensues aggressive and immediate symptom control is needed. Use morphine 5 to 10 mg IV push q 10 min, and/or midazolam, 2 to 4 mg IV push q 10 min, until distress is relieved. Adjust both infusion rates to maintain relief.
6. Remember that specific dosages are less important than the goal of symptom relief. A general goal should be to keep the respiratory rate < 30, heart rate < 100 and eliminate grimacing and agitation.
7. For symptoms refractory to the above treatments, use a barbiturate (e.g. pentobarbital), haloperidol or propofol.

References


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  Non-Physician: Clergy/Chaplains, Nurses

ACGME Competencies: Medical Knowledge, Patient Care
Keyword(s): ICU
Specific Disease and Organ System Category(s): ICU
Fast Fact and Concept #035: Information for patients and families about ventilator withdrawal (Part III)

2nd Edition

Author(s): Charles von Gunten, MD PhD and David E. Weissman, MD

Note: This is Part III of a three-part series; Part I reviewed a protocol for removing the ventilator (FF#33), Part II reviewed medications for symptom control (FF#34).

The physician’s counseling of families is a critical aspect of care for the dying patient who is to be removed from a ventilator. Ideally the family will be involved in the decision to withdraw the ventilator and thus apprised of the goals of care. Before withdrawal, the following issues should be discussed.

Potential outcome of ventilator withdrawal

Assuming all other life-sustaining treatments have been stopped, including artificial hydration and nutrition, there are several potential outcomes: rapid death within minutes (typically patients with sepsis on maximal blood pressure support), death within hours to days (see FF#3), or stable cardiopulmonary function leading to a different set of care plans, including potential hospital discharge. If the latter possibility is realistic, future management plans should be discussed prior to ventilator removal, since some families may desire to resume certain treatments, notably artificial hydration/nutrition. Generally, by the nature of the underlying illness and the established goals, it is fairly easy to predict which category will be operative, but all families should be prepared for some degree of prognostic uncertainty (see FF #30).

The procedure of ventilator withdrawal

Never make assumptions about what the family understands; describe the procedure in clear, simple terms and answer any questions. Families should be told before-hand the steps of withdrawal and whether or not it is planned/desired to remove the endotracheal tube (see FF#33). In addition, they should be counseled about the use of oxygen and medications for symptom control. Assure them that the patient’s comfort is of primary concern. Explain that breathlessness may occur, but that it can be managed. Confirm that you will have medication available to manage any discomfort.
Ensure they know that the patient will likely need to be kept asleep to control
their symptoms and that involuntary moving or gasping does not reflect
suffering if the patient is properly sedated or in a coma.
Explain how the family, clergy and others can be at the bedside before, during
and after withdrawal. If asked, explain that they can show love and support
through touch, wiping of the patient’s forehead, holding a hand and talking to
him or her.

Support the decision
Even though a family is able to make a definite decision for ventilator
withdrawal, such a decision is always emotionally charged. Families will
constantly second-guess themselves, especially if the patient appears to
linger following ventilator withdrawal. Physician support, guidance and
leadership is crucial, as the family will be looking to the physician to ensure
them that they are “doing the right thing”. Furthermore, it is common for
families to have concerns that their decision constitutes euthanasia or
assisted suicide—explicit counseling from a physician will be needed. Finally,
support needs to continue following death during the bereavement period
(see Fast Fact # 22).

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Adapted from: Emanuel, LL, von Gunten, CF, Ferris, FF (eds.). “Module 11:
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147.

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ACGME Competencies: Interpersonal and Communication Skills, Patient Care

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Specific Disease and Organ System Category(s): ICU
Impact of an Inpatient Palliative Care Team: 
A Randomized Controlled Trial

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ABSTRACT

Background: Palliative care improves care and reduces costs for hospitalized patients with life-limiting illnesses. There have been no multicenter randomized trials examining impact on patient satisfaction, clinical outcomes, and subsequent health care costs.

Objective: Measure the impact of an interdisciplinary palliative care service (IPCS) on patient satisfaction, clinical outcomes, and cost of care for 6 months posthospital discharge.

Methods: Multicenter, randomized, controlled trial. IPCS provided consultative, interdisciplinary, palliative care to intervention patients. Controls received usual hospital care (UC).


Measures: Modified City of Hope Patient Questionnaire, total health care costs, hospice utilization, and survival.

Results: IPCS reported higher scores for the Care Experience scale (IPCS: 6.9 versus UC: 6.6, p = 0.04) and for the Doctors, Nurses/Other Care Providers Communication scale (IPCS: 8.3 versus UC: 7.5, p = 0.0004). IPCS patients had fewer intensive care admissions (ICU) on hospital readmission (12 versus 21, p = 0.04), and lower 6-month net cost savings of $4,855 per patient (p = 0.001). IPCS had longer median hospice stays (24 days versus 12 days, p = 0.04). There were no differences in survival or symptom control.

Conclusions: IPCS patients reported greater satisfaction with their care experience and providers’ communication, had fewer ICU admissions on readmission, and lower total health care costs following hospital discharge.

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**IMPACT OF AN INPATIENT PALLIATIVE CARE TEAM**

**INTRODUCTION**

Care of patients with advanced illness has been recognized as suboptimal. Particularly in hospital settings, patients and families have reported inadequate pain and symptom relief as well as unwanted life-sustaining treatment at the end of life. Assistance for patients and families as they attempt to understand complex medical information including prognosis and treatment options appears to be less than adequate. Hospice referrals tend to be initiated late in the course of illness despite the positive association between hospice length of stay and family perceptions of the benefits.

In recent years, hospital-based palliative care (PC) programs have been developed to address these deficiencies. These interventions are designed to improve symptom management, help patients and families better understand prognosis and treatment options, clarify goals of care, and assist in planning for disease progression.

Interdisciplinary PC teams are believed to be particularly helpful in addressing the full spectrum of patients’ health, spiritual, and psychosocial needs, and aligning treatment choices with patients’ values and goals.

Evidence of the effectiveness of interdisciplinary inpatient PC in improving clinical outcomes, satisfaction with hospital care, and use of hospice is limited. Information on subsequent health services utilization is even less available. There have been no prospective, multisite, randomized control trials to assess the efficacy of inpatient PC interventions.

We hypothesized that an interdisciplinary inpatient palliative care consultative service (IPCS) would demonstrate improved symptom control, increase patient satisfaction with care and decrease the cost of health services received over the subsequent 6 months after hospital discharge.

**METHODS**

**Study design, protocol, and randomization**

IPCS was a three-site, prospective, randomized trial comparing outcomes of an IPCS to usual care (UC) in patients hospitalized with a life-limiting illness. Enrollment occurred between June 2002 and December 2003. Eligible patients were members of the same integrated health plan from three regions: Denver, Colorado, San Francisco, California, and Portland, Oregon. The study was approved by the Institutional Review Boards of the health plan and hospitals.

Eligible patients were 18 or more years of age, hospitalized with at least one life-limiting diagnosis, and whose attending physician indicated they “would not be surprised if the patient died within 1 year.” The effectiveness of this question in identifying patients who were appropriate for palliative care services has been reported previously. Patients were excluded if they had impaired cognitive status and no surrogate or were currently enrolled in hospice or other PC studies. Referrals were received from all medical services and inpatient units. Study enrollment occurred Monday through Friday.

Written informed consent was obtained from the patient or proxy before study participation and randomization. After a baseline questionnaire was administered the patient was randomly assigned to IPCS or UC using a computer-generated, randomized assignment list for each site. Following study randomization, IPCS was initiated for those patients randomly assigned to the intervention arm.

San Francisco and Portland hospitals were part of a managed care organization’s (MCO) delivery system. Denver’s community hospital had a contract with the MCO. The hospital size was 102, 225, and 383 beds, respectively. All hospitals had MCO hospitalist physicians. At two sites hospitalists served as the attending physicians. Portland’s hospital used a combination of MCO hospitalists and primary care internists. The majority of Portland patients (72%) were followed by hospitalists. All hospitals had social workers and chaplains on staff that provided direct patient services to UC patients.

**Description of the IPCS program**

The IPCS teams included a palliative care physician and nurse, hospital social worker and chaplain. In Denver and Portland the teams were newly formed for the study while San Francisco’s team had been operating for a year. All teams provided care in accordance with key palliative care components which were adapted from Weismann (Table 1).

The team met prior to each consultation to share what was known about the patient from the medical record, baseline questionnaire, and hospital providers. The entire team then met with the patient/family to address symptoms, diagnosis, prognosis, and goals of care.

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*Table 1: Palliative Care Components*

<table>
<thead>
<tr>
<th>Component</th>
<th>Description</th>
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<tbody>
<tr>
<td>Symptom management</td>
<td>Expertise in symptom control for pain, nausea, dyspnea, and other symptoms</td>
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<tr>
<td>Psychosocial support</td>
<td>Assistance with emotional and spiritual issues</td>
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<tr>
<td>End-of-life planning</td>
<td>Clear communication about treatment options and goals of care</td>
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<tr>
<td>Post-hospital care planning</td>
<td>Coordination of care after hospital discharge</td>
</tr>
</tbody>
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care. Psychosocial and spiritual concerns were identified and advance directive forms were discussed. After the patient/family meeting, the team convened briefly to synthesize a palliative care plan and organize follow-up by team members. IPCS provided consultation on intervention patients to the attending, involved subspecialists and staff on all aspects of PC, including treatment recommendations. The team was available Monday through Friday. A PC physician was on call after hours.

The teams collaborated with the attendings and discharge planners in preparing for the patient’s discharge. The PC discharge plan was communicated to the primary care physicians through documentation in an electronic medical record. If intervention patients were readmitted to the hospital they were again followed by IPCS for PC needs.

To ensure treatment consistency there were bi-weekly telephone conferences among the three sites to review cases and promote protocol adherence. Each site was visited early in the study to assess protocol adherence, and intervention patients’ medical records were reviewed to ensure that all treatment components were addressed.

### Table 1. Components and Core Features of a Palliative Care Consulta

<table>
<thead>
<tr>
<th>Components</th>
<th>Core features</th>
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<tbody>
<tr>
<td><strong>Setting the stage:</strong> Assessment of the patient/family knowledge and perception of disease treatment and prognosis</td>
<td>Ask what s/he knows or perceives Ask what s/he wants to know</td>
</tr>
<tr>
<td><strong>Discussion of medical issues</strong></td>
<td>Summarize current medical issues, including current diagnosis, treatments and prognosis Review what is important to patient e.g., comfort and pain control, going home, further curative treatments, life at all costs Assist patient to decide which treatments are advancing the goals of care and which are adding unnecessary burden Address patient wishes for intensity of intervention at EOL, i.e., DNR vs. other</td>
</tr>
<tr>
<td><strong>Assisting patient to identify personal goals for end-of-life care</strong></td>
<td>Identify surrogate decision marker</td>
</tr>
<tr>
<td><strong>Assessment and management of physical symptoms</strong></td>
<td>Review of symptoms and probable etiologies Assessment of symptom intensity and patient goals for symptom relief Assessment and subsequent reassessment of current treatment strategies Recommendations for symptom management</td>
</tr>
<tr>
<td><strong>Assessment and management of psychological, spiritual, and practical needs:</strong> fear of dying, anxiety about afterlife, denial of impending death, concerns about family and finances, patient support systems, and search for meaning</td>
<td>Assessment of the presence and intensity of these and other issues; how they may affect decision making Development of intervention strategies Help to normalize feelings, provide information, encourage short-term goal setting</td>
</tr>
<tr>
<td><strong>Assessment of discharge planning issues:</strong> determining options for EOL care and communicating that plan to other involved agencies and clinicians and other providers</td>
<td>Facilitate family meetings Work with other providers involved in the patient’s care Financial sources of support What is expected prognosis Document patient/family goals of care What are patient’s symptom control needs (assistance, technology, training) Discharge disposition What level and kinds of support are available outside the hospital Is a caregiver(s) present and what support is available to the caregiver Financial sources of support</td>
</tr>
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aAdapted from Wesisman.48

EOL, end of life; DNR, do not resuscitate.
Study outcomes and measures

The primary study outcomes were symptom control, levels of emotional and spiritual support, patient satisfaction, and total health services costs at 6 months postindex hospitalization. Secondary measures included survival, number of advance directives (ADs) at discharge, and hospice utilization within the 6 months postindex hospitalization (hospitalization during which study enrollment occurred).

Surveys were administered to patients or proxies at study enrollment and within 2 weeks following index hospitalization discharge to measure symptom control as well as emotional and spiritual support. Patient satisfaction was also measured within 2 weeks of index hospital discharge. Proxies were instructed to answer the survey items as they thought the patient would.

Symptom severity was measured using the Physical Area scale of the Modified City of Hope Patient Questionnaires (MCOHPQ). The Physical Area scale addresses pain, fatigue, sleep changes, nausea, constipation, diarrhea, dry mouth, change in appetite, and shortness of breath. Higher scores indicated greater symptom severity.

Patients rated their emotional and spiritual support using items from the MCOHPQ Emotional/Relationship Area and Spiritual Area scales. Emotional support items included: anxiety, burden to family, support they received, isolation, opportunity to discuss illness and possible death, and treatment wishes/goals. Higher scores indicated greater emotional burden. Spiritual support included: the importance of participation in spiritual or religious experiences from the Spiritual Area scale, and two items developed by the investigators: ability to find meaning in one’s life, and support given by religion or spiritual belief. Higher scores reflected greater support.

The patient’s satisfaction with their inpatient experience was measured by the MCOHPQ Place of Care Environment scale and the Doctors, Nurses/Other Care Providers Communication scale. The Place of Care Environment scale addressed experiences receiving pain management and symptom relief, psychological and social support, discharge planning, and end-of-life planning. Higher values indicated more positive feelings. The Doctors, Nurses/Other Health Care Providers Communication scale addressed the level of caring and respect a patient felt from their providers, as well as the opportunity, ease, and the level of understanding the patient had with their providers. Higher scores represented greater caring, respect and understanding between patients and their providers. A composite score for each scale was computed by summing the scores for all items in a scale and dividing the sum by the number of items completed. Cronbach α, a measure of internal consistency was computed for each scale. Cronbach α were: 0.66 for Physical scale, 0.18 for Emotional/Relationship scale, 0.65 for Spiritual scale, 0.65 for the Place of Care Environment scale, and 0.65 for the Doctors, Nurses/Other Health Care Providers Communication scale. These α indicate fair agreement among the individual items for the Physical and Spiritual scales but a lack of agreement for the Emotional/Relationship scale.

Statistical analyses

All analyses were performed using SAS 9.1 (SAS Institute Inc., Cary, NC). A p value = 0.05 was significant. Categorical variables were summarized as percentages; continuous variables as means or medians (for skewed data). Continuous measures for IPCS and UC patients were compared using t tests for normally distributed measures and Wilcoxon two-sample tests for measures with skewed distributions. Categorical measures were tested using χ² tests or Fisher’s exact test. All time to event measures (e.g., survival, days to hospice admission) were analyzed using Cox proportional hazard models.

Patients with life-limiting illnesses often have physical and cognitive limitations that necessitate the use
of proxies, which was the case in this study. We report the combined patient and proxy survey data here because analysis of the separate patterns of patient and proxy responses to the scales were similar.

Comparisons in total health costs between the IPCS and UC group used a non-linear model with a negative binomial distribution and log link. Costs were not transformed because the log link accounts for skewed distributions. The model was adjusted for site, age, gender, and the number of days a patient could use medical services. Costs are presented as total costs per patient. IPCS team costs were included in the net costs savings.

RESULTS

The IPCS received 1168 referrals for study enrollment (Fig. 1). Five hundred fifty-one patients did not meet inclusion criteria (cognitive impairment with no surrogate, were currently enrolled in hospice or other PC studies, or the attending did not approve study participation), were discharged or died prior to informed consent, refused to participate, or were excluded for undocumented reasons (Fig. 1). We randomly assigned 517 patients to IPCS (n = 280) or UC (n = 237). Five IPCS patients withdrew prior to the initiation of IPCS services at the encouragement of a family member, resulting in 275 IPCS patients. No patients were lost to follow-up.

Patient characteristics

Baseline characteristics are presented in Table 2. There were no differences in any baseline measures between the IPCS and UC groups except for the life-limiting diagnoses of stroke and end-stage renal disease (ESRD).

![Fig. 1. Inpatient palliative care study patient enrollment.](image-url)
Number of days from index hospital admission to study enrollment, days from enrollment to hospital discharge, and hospital LOS did not differ between the IPCS and UC patients (Table 3). There was no difference in mean total costs between groups for their index hospitalization (IPCS: $20,783; UC: $15,841, p < 0.08).

**Hospice use**

IPCS patients had significantly longer median hospice stays than UC participants (IPCS: 24 days; UC: 12 days, p = 0.04; Table 3). The median days from study enrollment to hospice admission was 1 day shorter for IPCS patients compared to UC patients but the difference was not significant (p = 0.14). The percentage of patients admitted to hospice did not differ (p = 0.50).

**Advance directives**

While there was no difference in the number of ADs at study enrollment (Table 2), IPCS patients completed significantly more ADs at hospital discharge than UC patients (91.1% vs. 77.8%; p < 0.001; Table 3).

**Survival**

There was no difference in survival between IPCS and UC. Median post enrollment survival was 30 days for IPCS and 36 days for UC (p = 0.08), and 173 IPCS patients (63%) and 132 UC patients (56%) died during the study period (p = 0.08). Significantly more IPCS patients (17.1%) died during their index hospitalization compared to UC patients (8.0%; p = 0.002; Table 3).

**Symptoms, emotional, spiritual support, and quality of life**

IPCS and UC mean enrollment and discharge scores for the Physical, Emotional/Relationship, Spiritual Area composite scales as well as the Quality of Life scale are shown in Table 4. There were no differences between groups for any scale.

**Satisfaction with hospital care and providers**

The IPCS group reported higher mean satisfaction for both the Place of Care Environment scale (IPCS: 6.8; UC: 6.4, p < 0.001) and the Doctors, Nurses/Other

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**Table 2. Patient Characteristics at Study Enrollment**

<table>
<thead>
<tr>
<th>Measure</th>
<th>IPCS (n = 275)</th>
<th>Usual care (n = 237)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance directives at study enrollment</td>
<td>158 (53.38)</td>
<td>138 (62.2)</td>
<td>0.53a</td>
</tr>
<tr>
<td>Age, mean (SD)</td>
<td>73.6 (12.6)</td>
<td>73.1 (13.2)</td>
<td>0.68b</td>
</tr>
<tr>
<td>Comorbidities at study enrollment, mean (SD)</td>
<td>3.2 (2.2)</td>
<td>3.5 (2.3)</td>
<td>0.11b</td>
</tr>
<tr>
<td>Composite physical area scale at enrollment, mean (SD)</td>
<td>5.2 (1.8)</td>
<td>5.1 (1.8)</td>
<td>0.72b</td>
</tr>
<tr>
<td>Composite emotional/relationship area scale at enrollment, mean (SD)</td>
<td>6.3 (1.9)</td>
<td>6.2 (1.7)</td>
<td>0.67b</td>
</tr>
<tr>
<td>Composite spiritual area scale at enrollment, mean (SD)</td>
<td>6.8 (2.7)</td>
<td>6.5 (3.0)</td>
<td>0.27b</td>
</tr>
<tr>
<td>ECOG score, median (interquartile range)</td>
<td>2 (2.3)</td>
<td>2 (2.3)</td>
<td>0.68c</td>
</tr>
<tr>
<td>Quality of life, median (interquartile range)</td>
<td>4 (1.7)</td>
<td>4 (2.6)</td>
<td>0.93c</td>
</tr>
<tr>
<td>Female, Number, number (%)</td>
<td>162 (59)</td>
<td>121 (51)</td>
<td>0.07a</td>
</tr>
<tr>
<td>Life-limiting diagnosis, number (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>64 (27.3)</td>
<td>95 (34.4)</td>
<td>0.09a</td>
</tr>
<tr>
<td>CHF</td>
<td>21 (8.9)</td>
<td>17 (6.2)</td>
<td>0.24a</td>
</tr>
<tr>
<td>MI</td>
<td>3 (1.3)</td>
<td>6 (2.2)</td>
<td>0.52a</td>
</tr>
<tr>
<td>Other heart disease</td>
<td>7 (3.0)</td>
<td>3 (1.1)</td>
<td>0.20a</td>
</tr>
<tr>
<td>COPD</td>
<td>31 (13.2)</td>
<td>35 (12.7)</td>
<td>0.86a</td>
</tr>
<tr>
<td>Other pulmonary disease</td>
<td>3 (1.3)</td>
<td>3 (1.1)</td>
<td>1.00a</td>
</tr>
<tr>
<td>ESRD</td>
<td>10 (4.3)</td>
<td>2 (0.7)</td>
<td>0.02c</td>
</tr>
<tr>
<td>Organ failure</td>
<td>29 (12.3)</td>
<td>28 (10.1)</td>
<td>0.48a</td>
</tr>
<tr>
<td>Stroke</td>
<td>20 (8.5)</td>
<td>10 (3.6)</td>
<td>0.02c</td>
</tr>
<tr>
<td>Dementia</td>
<td>8 (3.4)</td>
<td>13 (4.7)</td>
<td>0.51a</td>
</tr>
</tbody>
</table>

*a*χ² for proportions or Fisher’s exact test (for tables with uneven margins and/or cells within n = 5).

*bt* test.

*c*Wilcoxon two-sample test.

IPCS, inpatient palliative care service; SD, standard deviation; ECOG, Eastern Cooperative Oncology Group; CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; MI, myocardial infarction; ESRD, end-stage renal disease.
Health Care Providers Communication scale (IPCS: 8.3; UC: 7.2, \( p < 0.001 \); Table 5).

Total health care expenditures

Total mean health costs for the IPCS group were lower by $6,766 per patient compared to UC patients (IPCS: $14,486; UC: $21,252, \( p = 0.001 \)). After subtracting the cost of staffing the IPCS ($1,911 per patient), the net savings was $4,855 per patient. Cost savings were largely driven by a significant difference in hospital readmission costs (IPCS: $6,421 per patient versus UC: $13,275 per patient, \( p = 0.009 \)). There was no difference in the number of hospital readmissions but IPCS patients had significantly fewer ICU stays on readmission (IPCS: 12; UC: 21, \( p = 0.04 \); Table 6).

**DISCUSSION**

Key findings include greater IPCS patient satisfaction with hospital care and providers, longer hospice length of stay, more advanced directives at index hospitalization discharge, no difference in overall survival, reduced ICU admissions on subsequent hospitalization, and lower total health costs.

We believe greater patient satisfaction was achieved due to IPCS addressing the patient’s and family’s need for information and facilitating their active participation in decisions regarding their medical care. Increased patient satisfaction has been reported from previous research on palliative care interventions.\(^{28,29,43}\)

We found no differences in physical symptoms which is inconsistent with other studies on inpatient palliative care interventions.\(^{23,38,42,43}\) In particular, we found no differences in pain symptoms from study enrollment to index hospitalization discharge. There are several possible explanations. First, patients in this study reported relatively low physical symptoms at study enrollment. The mean pain rating on a scale of 1 to 10 was 3.4 suggesting that pain was less than in other reported populations whose symptoms were more severe.\(^{23,42}\) Second, the average index hospital-

---

**Table 3. Comparisons for the Index Hospitalization, Advance Directives, Hospice Use, and Survival**

<table>
<thead>
<tr>
<th>Measure</th>
<th>IPS (n = 275)</th>
<th>Usual care (n = 237)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admission to study enrollment (days), median (interquartile range)</td>
<td>3 (2.7)</td>
<td>4 (2.7)</td>
<td>0.36*</td>
</tr>
<tr>
<td>Study enrollment to discharge or death in the hospital (days), median (interquartile range)</td>
<td>3 (1.6)</td>
<td>2 (1.5)</td>
<td>0.10*</td>
</tr>
<tr>
<td>Index Hospital length of stay (days) median (interquartile range)</td>
<td>7 (4.12)</td>
<td>7 (4.12)</td>
<td>0.57*</td>
</tr>
<tr>
<td>Study enrollment to hospice admission (days), median (interquartile range)</td>
<td>2 (0.23)</td>
<td>3 (0.37)</td>
<td>0.09*</td>
</tr>
<tr>
<td>Survival from study enrollment (days), median (interquartile range)</td>
<td>30 (6,104)</td>
<td>36 (13,106)</td>
<td>0.08*</td>
</tr>
<tr>
<td>Survival from study enrollment for patients who did not die during index hospitalization, median (interquartile range)</td>
<td>43 (17,134)</td>
<td>43.5 (16,117)</td>
<td>0.80*</td>
</tr>
<tr>
<td>Days to hospice, median (interquartile range)</td>
<td>2 (0.23)</td>
<td>3 (0.37)</td>
<td>0.14*</td>
</tr>
<tr>
<td>Hospice length of stay (days), median (interquartile range)</td>
<td>24 (7.94)</td>
<td>12 (4.48)</td>
<td>0.04*</td>
</tr>
<tr>
<td>Index Hospital length of stay (days) median (interquartile range)</td>
<td>7 (4.12)</td>
<td>7 (4.12)</td>
<td>0.57*</td>
</tr>
<tr>
<td>Died during index hospitalization, number (%)</td>
<td>47 (17.1)</td>
<td>19 (8.0)</td>
<td>0.002d</td>
</tr>
<tr>
<td>Advance directives at discharge, number (%)</td>
<td>224 (91.1)</td>
<td>172 (77.8)</td>
<td>&lt; 0.001d</td>
</tr>
<tr>
<td>Died during study, number (%)</td>
<td>173 (62.9)</td>
<td>132 (55.7)</td>
<td>0.08*</td>
</tr>
<tr>
<td>Patients admitted to hospice, number (%)</td>
<td>103 (37.1)</td>
<td>96 (40.7)</td>
<td>0.50*</td>
</tr>
<tr>
<td>Total index hospitalization costs ($), mean (SD)</td>
<td>20,783 (40,088)</td>
<td>10,864 15,841 (18,959)</td>
<td>8,868 0.08*</td>
</tr>
<tr>
<td>median</td>
<td>10,864</td>
<td>15,841 (18,959)</td>
<td>8,868 0.08*</td>
</tr>
</tbody>
</table>

\(^{a}\)Cox proportional hazards model.

\(^{b}\)Wilcoxon two-sample test.

\(^{c}\)Chi-square test.

\(^{d}\)Patients with no advance directive at study enrollment: N: IPCS = 95, UC = 80. Not all subjects had a documented presence or absence of an advance directive at study enrollment.

\(^{e}\)Generalized linear model adjusted for age, gender, and study site.

IPCS, inpatient palliative care service; SD, standard deviation; ECOG, Eastern Cooperative Oncology Group performance scale.
The impact of an inpatient palliative care team on hospitalization LOS after study enrollment was 4.9 days, a shorter time for the IPCS team to manage complex physical symptoms compared to studies with longer interventions.23,42,43 Finally, our patient population survived for a longer period of time, indicating they might be earlier in their disease state than other inpatient palliative care patients.34,58

There was no difference in the proportion of patients enrolled in hospice, but IPCS patients had longer hospice stays. MCOs have higher rates of hospice utilization and longer hospice stays compared to fee for service.55 As all participants were MCO members, it is possible that IPCS would not be able to increase an already high hospice enrollment rate. Finally, patients and their families may not have considered hospice at their index hospitalization because this was not an option they felt necessary at this stage in the patient’s illness.

We were not surprised that we had significantly more ADs at index hospital discharge because ADs were addressed with each intervention patient. Increased ADs subsequent to palliative care interventions is consistent with the literature.27

There was no difference in the number of inpatient readmissions between the IPCS and UC, but IPCS patients had lower inpatient readmissions costs. These lower readmission costs are partially explained by fewer ICU admissions. Reduced ICU admissions may have been due to more clearly defined patient goals of care and more effective communication of these goals in the medical record and through advance directives. Other studies have found decreased ICU admissions.34 Overall survival between IPCS and UC patients did not differ. However, more IPCS patients died during their index hospitalization, which was attributed to a

Table 4. Composite Burden Scale Scores at Study Enrollment and Index Hospitalization Discharge for Combined Patient and Proxy Responses

<table>
<thead>
<tr>
<th>Composite score</th>
<th>IPCS Study enrollment Mean (SD)</th>
<th>n</th>
<th>IPCS Hospital discharge Mean (SD)</th>
<th>n</th>
<th>UC Study enrollment Mean (SD)</th>
<th>n</th>
<th>UC Hospital discharge Mean (SD)</th>
<th>n</th>
<th>p valuea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical area scaleb</td>
<td>5.2 (1.8)</td>
<td>240</td>
<td>4.0 (1.7)</td>
<td>186</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional/relationship area scalec</td>
<td>6.3 (1.9)</td>
<td>243</td>
<td>7.0 (1.4)</td>
<td>184</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual area scale</td>
<td>6.8 (2.7)</td>
<td>254</td>
<td>6.6 (2.5)</td>
<td>202</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-reported quality of life</td>
<td>4.1 (3.3)</td>
<td>266</td>
<td>6.4 (2.3)</td>
<td>199</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Generalized linear model with hospital discharge score as the independent variable and the study enrollment score as covariate.

b11-point scale: 0 = no problem, 10 = severe problem; higher score = greater physical discomfort.

c11-point scale: 0 = none at all, 10 = completely; higher score = greater emotional burden.

d11-point scale: 0 = not at all, 10 = a great deal; higher score = greater importance attached to spiritual aspects of one’s life.

e11-point scale: 0 = very bad, 10 = excellent.

IPCS, inpatient palliative care service; UC, usual care; SD, standard deviation.

Table 5. Composite Satisfaction Scale Scores Index at Index Hospitalization Discharge for Combined Patient and Proxy Responses

<table>
<thead>
<tr>
<th>Composite score</th>
<th>IPCS Mean (SD)</th>
<th>n</th>
<th>UC Mean (SD)</th>
<th>n</th>
<th>p valuea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place of care environment scaleb</td>
<td>6.8 (1.0)</td>
<td>156</td>
<td>6.4 (1.1)</td>
<td>139</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Doctors, nurses/other health care providers</td>
<td>8.0 (1.4)</td>
<td>185</td>
<td>7.4 (1.7)</td>
<td>156</td>
<td>&lt; 0.001</td>
</tr>
</tbody>
</table>

*Generalized linear model.

b11-point scale: 0 = none at all, 10 = completely; higher score = greater positive feeling about care environment.

c11-point scale: 0 = not at all, 10 = a great deal; higher score = greater communication between patient and providers.

IPCS, inpatient palliative care service; UC, usual care; SD, standard deviation.
difference at one site. IPCS patients at this site had a median 3 day longer hospital stay than the UC group. This site’s team reported difficulty transitioning patients to other care venues near the end of life. There was no difference in mortality between IPCS and UC patient over a 14-day period postenrollment, whether or not they were still hospitalized, indicating that overall mortality was not different at that site.

The IPCS intervention did not vary among sites with respect to the components or core features of the intervention. However, uniqueness in the hospital culture, variability in palliative care staffing levels, patient support available at discharge, individual team members’ palliative care experience, and the functionality and maturity of each team did vary between sites as would be expected. Further study would be needed to understand if any of these factors might affect patient outcomes.

Other areas that would benefit from future research include which components of the palliative care intervention are most effective in achieving positive outcomes and how to apply the interdisciplinary palliative care team in other care settings.

We identified two study limitations. One limitation of the study was the lack of some measurable process measures, e.g., what symptoms and issues were helped by which components of the IPCS. A second limitation was participants in this study were members of a health plan with an integrated medical delivery system which may limit generalization of study outcomes in other settings.

This study provides evidence for the positive impact of IPCS consultations on satisfaction with care and decreased health care costs. It also contributes new information on the impact of this service on ICU admissions and hospice utilization. Based on this data, all three sites are continuing to offer palliative care to hospitalized members. In addition, the integrated health plan is implementing new IPCS programs nationally.

ACKNOWLEDGMENTS

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ABSTRACTS


McGrady K, Beane J: Outcomes of an Interdisciplinary Inpatient Palliative Care Service: A Randomized Controlled Trial.

Conner D: Differences in survival, hospice admission, and hospice length of stay for patients randomized to either an inpatient palliative care team intervention or to usual care. American Geriatrics Society Annual Meeting. Orlando FL: May 2005.


REFERENCES


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Palliative Care for Patients With Head and Neck Cancer

“I Would Like a Quick Return to a Normal Lifestyle”

Nathan E. Goldstein, MD
Eric Genden, MD
R. Sean Morrison, MD

THE PATIENT’S STORY

Mr K is a 57-year-old financial analyst with a long history of precancerous and cancerous oral lesions. Although his medical history includes hypertension, diabetes mellitus, and HIV infection (well controlled with antiretroviral treatments), he has no risk factors for oral cancer, specifically no tobacco use or significant alcohol intake. In 1997, he developed a tongue lesion that demonstrated dysplasia. It was treated with topical steroids, and then both laser and surgical excision. The lesion recurred in 1999 and a biopsy revealed superficially invasive well-differentiated squamous cell carcinoma. He underwent wide resection with all margins clear of carcinoma, but with residual dysplasia at the edges.

He was followed up closely and in April 2006 began experiencing worsening tongue pain. Biopsy at this time showed recurrence of his squamous cell carcinoma. He was then referred to Dr U, who performed a right partial glossectomy and ipsilateral neck dissection. Pathology from the tongue specimen showed carcinoma extending to the lateral margin. At this point, mandibular resection and reconstruction with a free fibula flap was undertaken. Intraoperative frozen section margins did not show evidence of cancer, but on final pathological examination, however, there was extensive involvement of the mandible to the lateral margin. Mr K was taken back to the operating room for a third resection and reconstruction with a second free fibula flap. After the operation, he underwent radiation therapy to the neck. Currently, 3 months after completion of radiation therapy, he appears to be free of disease.

During his operations and radiation therapy, Mr K lost nearly 20 pounds. He remains dependent on liquid artificial hydration and nutrition, delivered through a gastrostomy tube. He has difficulty controlling his oral secretions. His speech is intelligible but significantly different from his former pat-...
Palliative Care for Patients With Head and Neck Cancer

Palliative care is interdisciplinary care that provides support for the physical, emotional, and psychological suffering of patients with any advanced illness, regardless of age, diagnosis, or life expectancy. The goal is to prevent and relieve suffering and to improve quality of life for people facing severe, complex illness. It differs from traditional hospice or end-of-life care in that patients who receive palliative care can also continue to receive curative or life-prolonging treatments. This distinction is particularly important in the case of patients with head and neck cancers because these patients often have a relapsing course that is marked by periods of freedom from disease and symptoms, interspersed with bouts of serious illness, debility, and numerous physical and psychological symptoms including pain, dysphagia, weight loss, disfigurement, depression, and xerostomia. Suggestions for treatment of symptoms discussed herein come from a comprehensive search of both PubMed and the Cochrane Review databases.

Epidemiology of Head and Neck Cancer

An estimated 30,000 people are diagnosed with head and neck cancers annually in the United States, and approximately 7,500 individuals die of these cancers annually. The phrase “head and neck cancer” refers to a diverse group of diseases that include primary malignancies of the oral cavity, oropharynx, larynx, sinuses, and skull base. These malignancies primarily affect men (with a ratio of nearly 2:1) and are strongly associated with cigarette smoking and alcohol consumption. There has been increasing evidence in the last several years of an epidemiological link between human papillomavirus and head and neck cancers, even in the absence of cigarette smoking or alcohol consumption.

Although treatment options for head and neck cancer have evolved rapidly over the last 30 years, prognosis for patients with locally advanced disease still remains poor. Five-year survival rates for patients with head and neck cancer (all types and stages combined) is 59%. The mainstay of current therapies involves a combination of surgery, radiation, and chemotherapy; the sequence and timing of these interventions depends on both origin of the malignancy as well as its stage. Although these treatment modalities have increased the disease-free interval for patients with head and neck cancers, cure rates have not dramatically changed over the last 50 years. In other words, while the cure rates have not improved, patients are living longer with quiescent, subclinical disease. (A comprehensive outline of interventions and survival rates based on cancer type and stage is available elsewhere.) As patients live longer with the consequences of the disease and its treatment, primary care physicians need to be familiar with the common adverse effects and ways to alleviate them.

Physical Symptoms in Patients With Head and Neck Cancer

Dr U: I think he’s had some of the typical problems and he’s had some of the more extreme problems along the continuum of what patients with oral cancer deal with. One of the primary problems for patients with oral cancer is high recurrence rate... This patient has gone through that. He’s had multiple operations, which I know have been very taxing on him emotionally. He’s suffered all the sequelae that go along with surgery, primarily radiation, which seemed to be much harder on him than the surgery, which is usual for the patients with oral cancer.

Mr K: I had followed up with my surgeon’s associate once or twice a year and was disappointed to find that the cancer had returned last year. Over the years, once in a while, they had done biopsies, but they always came back negative; this time it was positive. When I had the earlier surgery in 1999, it affected my ability to speak and eat normally. I also had concerns about the pain involved in recovering from the surgery. When it was positive. When I had the earlier surgery in 1999, it had done biopsies, but they always came back negative; this time it was positive. When I had the earlier surgery in 1999, it affected my ability to speak and eat normally. I also had concerns about the pain involved in recovering from the surgery.

Medical symptoms, including pain, xerostomia, mucositis, difficulty swallowing, loss of taste, and change of speech. He would also have some long-term effects. Those would be a change in his speech pattern and, from the radiation therapy in particular, he would have xerostomia because of the damage to the salivary glands.

Mr K: Essentially the main drawbacks were the side effects and the fact that I am still not eating very well. Most of my nutrition is taken through a tube. It affects me because I can’t travel a very far distance [from home] without having to deal with the tube feeding. It is cumbersome and somewhat messy. So, I don’t want to go too far.

Patients with head and neck cancer can have a variety of physical symptoms, including pain, xerostomia, mucositis, difficulties with swallowing, and changes in speech and taste (Table). These symptoms may result from the tumor, acute adverse effects from treatments, or long-term sequelae of therapies.

Pain

Mr K: Radiation included rather unpleasant side effects. It’s painful and I got burns around my chin and neck. I had pain medication, and I put topical solutions on the areas of skin that were affected. I also had ulcers on my lips and yeast infections in my mouth. There was also bleeding in my mouth.

Although all patients with cancer may experience pain, individuals with head and neck cancer often have etiologies and pathophysiological mechanisms for pain that differ from other malignancies. Pain in the mouth or neck may be a presenting symptom, and it also may be a marker of recurrence. Pain re-
PALLIATIVE CARE FOR PATIENTS WITH HEAD AND NECK CANCER

Table. Common Symptoms Encountered in Patients With Head and Neck Cancer and Suggested Treatments

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Treatment</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Opioids</td>
<td>May need to be given via alternate route (eg, transdermal fentanyl patches, morphine elixir via gastrostomy tube)</td>
</tr>
<tr>
<td>Mucositis</td>
<td>Allopurinol mouthwash</td>
<td>Evidence supporting use of these agents is weak</td>
</tr>
<tr>
<td></td>
<td>Granulocyte-macrophage colony-stimulating factor Immunoglobulins</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Human placental extract</td>
<td></td>
</tr>
<tr>
<td>Dysphagia</td>
<td>Consultation with speech and language pathologist Artificial hydration and nutrition</td>
<td>Degree of dysphagia depends on origin of tumor and types of treatments. May be transient or permanent, may be severe and lead to dehydration or malnutrition</td>
</tr>
<tr>
<td>Xerostomia</td>
<td>Frequent intake of water, ice chips Use of sugarless candy or gum Artificial saliva Pilocarpine (starting dose 2.5 mg enterally 3 times daily)</td>
<td>Based on common practice, evidence is weak; should be left to patient preference within boundaries of what is deemed medically indicated (eg, avoid water if significant aspiration risk). Pilocarpine has multiple adverse effects, which may limit its use, particularly in elderly patients</td>
</tr>
<tr>
<td>Change in speech</td>
<td>Consultation with speech and language pathologist Adaptive devices (eg, amplifier)</td>
<td>Many patients can relearn speech so this symptom does not always interfere with long-term function, but speech may not return to baseline patterns</td>
</tr>
<tr>
<td>Decreased quality of life</td>
<td>Supportive treatments, including counseling and psychotherapy</td>
<td>In many patients, quality of life will return to baseline level over the long term</td>
</tr>
<tr>
<td>Depression</td>
<td>Emotional support Referral to psychotherapy, counseling Antidepressant medications</td>
<td>May be transient or prolonged; if patients are treated with antidepressants, adverse effects and interactions with other medications should be considered when selecting the medications</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Emotional support Referral to psychotherapy, counseling Anxiolytics</td>
<td>Anxiolytics can be associated with fatigue, delirium</td>
</tr>
</tbody>
</table>

Anxiolytics can be associated with fatigue, delirium

Consultation with speech and language pathologist is useful for many of these conditions as well.

Sialorrhea and Xerostomia

Problems with controlling and producing saliva are troublesome treatment complications of head and neck tumors. Indeed, Mr K reported drooling postoperatively due to the loss of the normal architecture of his mouth caused by a resection of a portion of his mandible. Even though these hypersecretory symptoms can sometimes be addressed solely by swallowing and speech techniques taught by a speech pathologist, patients may benefit from pharmacological treatment with anticholinergic medications (eg, glycopyrrolate, hyoscyamine) to dry secretions. In older adults, caution is warranted in using these medications.

Topical agents such as low-potency steroid creams, topical acid-containing creams (such as hyaluronic or ascorbic acid), and aloe vera have been studied for both the prevention and treatment of acute radiation-induced skin reactions, but a systematic review found no benefit from these agents. As such, clinical experience suggests that initial use of a plain, nonstained, lanolin-free hydrophilic cream may be helpful for patients with skin discomfort due to radiation, but these creams should be discontinued if skin breakdown occurs. Itching resulting from radiation may be treated with low-potency topical steroids, but caution is warranted because these agents may lead to skin thinning if used for a prolonged period. Severe pain resulting from radiation may be managed with systemic opioids if necessary. Long-term complications can occur within 2 to 4 months after completion of treatment and include changes in skin texture, fibrosis, and atrophy of soft tissues. Chronic pain in the radiation field can occur but is not common. Skin changes may be more severe if chemotherapy is added to the treatment regimen.

Source: www.jama.com at Mt Sinai School Of Medicine, on April 15, 2008
due to their multifaceted adverse effects profile (eg, orthostasis, constipation, urinary retention) and their propensity to induce delirium.21

As Dr U mentioned, xerostomia is also a complication of these malignancies, particularly in patients who undergo radiation therapy. The addition of chemotherapy to radiotherapy further increases the likelihood of developing xerostomia.34 Saliva is necessary for speech and eating, and it also serves to clean the mouth and reduce cavities. As such, the loss of saliva production can lead to difficulty eating and swallowing, trouble with speech, development of dental caries, and decreased quality of life.19 Because the radiation therapy destroys the glands that make saliva, higher doses are associated with more severe changes, which may be irreversible.35 Commonly used palliation for xerostomia includes drinking water frequently to keep the mouth lubricated, use of ice chips, and artificial saliva, which combines water with lubricants.18 Sucking on sugarless candy or chewing gum can also stimulate salivary flow.18 Pilocarpine, started at a dose of 2.5 mg by mouth 3 times daily that can be titrated up to 10 mg 3 times a day, is a parasympathomimetic compound that has been shown to improve patients’ symptoms to a certain extent,19,20 but its adverse effect profile (eg, sweating, rhinorrhea, urinary frequency) may limit its use.36

Mucositis

Mucositis is an inflammation of the mucosal membranes lining the gastrointestinal tract and frequently affects the mouth and pharynx of patients with head and neck cancer who undergo radiation therapy.17 As with xerostomia, the prevalence increases with the addition of chemotherapy.34 Mucositis can be extremely painful and result in the inability to eat, swallow, or speak. The discomfort can be so significant that it interrupts treatment plans.38 This condition can occur in either the mouth or pharynx and typically begins about 10 to 14 days after the commencement of radiation treatment (which is the length of time needed for the oral mucosa to regenerate, a process impeded by radiotherapy).21 The condition usually begins to abate 4 to 6 weeks after the completion of radiation.17 Clinically, the mucosal tissue may appear white and patchy at first and then may progress to erythema and, at times, ulcer formation. Mucositis can be exacerbated by superinfection by either Candida or oral bacterial flora. Numerous agents have been used in attempts to either prevent, reduce the severity of, or treat mucositis.15,30,60 These range from non-pharmacological treatments such as the use of ice chips, honey, and meticulous oral hygiene to local treatments (eg, topical lidocaine, sucralfate, “magic mouthwash” — a combination that varies by institution but often contains viscous lidocaine, diphenhydramine, and aluminum hydroxide41) to systemic treatments (eg, etoposide, granulocyte-macrophage colony-stimulating factor [GM-CSF]). Unfortunately, the data to support the use of many of these agents come from poorly designed studies whose results are often equivocal. In a recent comprehensive meta-analysis of agents to prevent or reduce the severity of mucositis, the Cochrane Collaboration determined that only 2 interventions showed promise in patients with head and neck cancer: amifostine (a free radical scavenger dosed at 200 mg/m² and given intravenously before radiation treatment42-44) and hydrolytic enzymes.60 In terms of treating mucositis, a different meta-analysis by the same group showed that 4 agents were statistically beneficial for the treatment of mucositis: allopurinol mouthwash, GM-CSF, immunoglobulins, and human placental extract.15 However, in both prevention and treatment trials, the effect size for these agents is quite small and problems with study design often make these conclusions unreliable.15,46 Systemic opioids (given orally, intravenously, or transdermally) effectively treat the pain of mucositis13 and should be used aggressively if local treatments do not result in desired pain relief. Patients with severe mucositis need to be closely monitored to prevent malnutrition or dehydration and may require hospitalization if severe pain or dehydration requires intravenous medications or fluids.

Dysphagia and Odynophagia

Difficulties with swallowing are almost universal symptoms for patients with head and neck cancer and may stem from the primary tumor or develop as a sequelae of surgery or radiation. Swallowing difficulties can take the form of either dysphagia or odynophagia. Artificial hydration and nutrition, most often delivered through a gastrostomy tube, is commonly used in patients as a temporary mechanism to ensure adequate nutrition and hydration during the healing process.17 Unlike patients with other forms of advanced disease for whom data demonstrate that artificial hydration and nutrition is not beneficial and may even be harmful,45-47 there is less controversy about the benefit of artificial hydration and nutrition in this population. Mr K’s concerns about his inability to travel while using gastric feeding are common. Delivering larger quantities of artificial hydration and nutrition in a short period of time at regular intervals (bolus feeding) can help liberate these patients from the use of a pump and the need to be attached to external encumbrances. Consultation with a nutritionist is essential to ensure that patients receive adequate intake of calories, protein, and water. In those patients with advanced disease who require large-scale resections or permanent tracheostomy, the need for artificial nutrition may be lifelong. In addition to addressing swallowing difficulties, artificial nutrition may be needed to supplement caloric intake for patients who experience severe anorexia due to alterations in smell or taste. Systemic opioids may also be effective for those patients with severe pain that restricts their ability to swallow.

Difficulties With Speech

Depending on the nature of a patient’s cancer and the surgical procedures necessary to treat it, changes in speech may be transient or permanent. Alterations to the lips, tongue, teeth, hard or soft palate, and larynx can all result in different patterns of speech or voice disorders.23 In the case of Mr K, although his voice will never return to its preoperative character and quality, he is able to speak without the use of an assistive device.
For patients with more advanced disease or who require laryngeal resection, amplifying devices or alternate speaking techniques (eg, tracheoesophageal speech) must be used. Close collaboration with speech and language pathologists who specialize in the care of patients with head and neck malignancies should begin early in the course of a patient’s treatment.

**Psychological Symptoms in Patients With Head and Neck Cancer**

**DR U:** One of the primary problems for patients with oral cancer is the high recurrence rate. This patient has gone through that. He’s had multiple operations, which I know have been very taxing on him emotionally. . . . Having said that, he has been surprisingly good at getting back to normal life. . . . His partner has been extremely supportive and helped him through therapy and the difficult decisions. . . . I think that the support he has gotten from his partner has improved his quality of life.

**Mr K:** Having cancer can be very depressing. I can’t say that I had severe depression, but I did have some intermittent bouts of depression. . . . While it is comforting that the cancer has been removed and the radiation will try to prevent the return, I would like a quick return to a normal lifestyle. I would very much like to eat real food again and converse as normally as possible.

**Body Image and Functional Outcomes**

Although physical symptoms must be considered in the care of patients with head and neck malignancies, the constellation of these symptoms and their impact on patients’ body image and overall quality of life are equally important to consider. Mr K sumns up well the frustrations experienced by this group of patients. Although cure is possible for many, patients encounter numerous setbacks while undergoing the procedures and healing necessary along the road to recovery. Changes in body appearance—and body image—are almost universal. Since the 1980s, when surgeons began to consider aesthetics and function as well as treatment, reconstructive procedures have improved dramatically, due in part to collaboration between otolaryngologists and plastic surgeons. Patients who undergo surgery by a skilled surgical team may be left with little to no outward physical changes. The introduction of microvascular-free tissue transfer, a technique that transfers skin, muscle, bone, or all 3 from one part of the body to the neck for reconstruction of the tongue, jaw, and face, provided surgeons with the means to improve a patient’s quality of life by improving both functional and cosmetic outcomes.

More recently, the application of robotic surgery and endoscopic techniques allows the resection of tumors without the deforming facial incision used previously. These new techniques have been developed in the past several decades, but few data on their impact on patients’ quality of life and functional outcomes are available. However, pending such data, patients should be encouraged to seek out medical centers that practice such procedures to maintain cosmetics and function.

**Quality of Life and Depression**

Because patients see themselves every day in the mirror and the face is a key element in the way we express ourselves to the outside world, even small alterations in visage can have a large adverse impact on patients’ body image and self-esteem. Likewise, because of difficulties with swallowing and nutrition as well as the cachexia that is associated with cancer, these patients may lose a great deal of weight. Due to these changes in appearance and the impact that both the malignancy and its treatments have on physical functioning and self-image, patients with head and neck cancer may experience a significantly worsened quality of life. Long-term studies of these patients, however, show that after a period of 12 to 36 months, self-rated quality of life may return to baseline in more than 50% of patients. A patient’s best achievable quality of life is dependent on factors such as current pathlogy, stage at diagnosis, and surgical or medical interventions used. In spite of this eventual return to satisfaction with their quality of life, the period from diagnosis to full recovery may be marked by symptoms of frustration, hopelessness, and depression. Studies have shown that 20% to 50% of patients with head and neck cancers may have moderate to severe depression at some point after diagnosis. Whether these symptoms are a true episode of major depression or an adjustment reaction with depressive features, the use of antidepressant medications often helps patients with head and neck cancers. Choice of specific medications (eg, selective serotonin reuptake inhibitors [SSRIs] vs norepinephrine and dopamine reuptake inhibitors) should be guided by patients’ other physical symptoms and the medication’s adverse effect profile. For example, patients with weight loss may benefit from the tetracyclic antidepressant mirtazapine, which has been shown to cause weight gain in some patients, and patients with xerostomia should not receive tricyclic antidepressants due to their anticholinergic properties.

**Anxiety**

In addition to depression, the high recurrence rate of head and neck cancers may result in a constant sense of anxiety relating to concerns about relapse. Mr K has lived with his cancer for over a decade, a not-uncommon scenario for patients with head and neck malignancies. The anxiety caused by this uncertainty can be particularly pervasive, affecting patients and their families in multiple areas of function. Psychotherapy and support groups may be beneficial to patients with head and neck malignancies and their families. If this anxiety impairs function or quality of life, treatment of anxiety with medications such as benzodiazepines or SSRIs may be indicated. By asking patients about their concern of recurrence, clinicians can begin a discussion that allows patients to talk about their fears while at the same time offering therapeutic options. To begin such a conversation, a clinician may say, “Do you worry that every pain or discomfort means that the cancer is back?” or “Some patients find that speaking with other individuals with head and neck cancer can be helpful. Would you like me to provide you information on support groups?”
Guilty and Self-blame

For decades the epidemiological links between head and neck cancers and both tobacco and alcohol consumption have been well established and are thought to be mediated through the creation of oncogenes and ultimately tumor formation. Although some patients may blame themselves and feel they caused their own illness, patients may also feel guilt about the toll that the illness takes on their family and caregivers. Eating is a major social, cultural, and religious ritual in society, and patients with head and neck cancer often cannot participate in this activity. Even going out to dinner can become an impossible task, and patients may often be concerned about the impact this has on their family. Likewise, facial disfigurement—even if only temporary—may make it emotionally difficult for patients to leave the house, which can change the dynamic between patients and their loved ones. Feelings of guilt and self-blame in patients with head and neck cancer are therefore not only related to their own role in their illness but also to the belief that they are to blame for the impact the illness has on the quality of life of their loved ones. Physicians can assist patients with these feelings by encouraging them to talk about them with their loved ones, and even facilitating these conversations. For example, if a patient is accompanied to an office visit with a caregiver, the clinician can ask both of them, “What role has the illness taken on your relationship?” or even more directly, “Are you finding it difficult to eat out in public? How are you handling the changes imposed by the cancer on your social life or religious practices?”

Interdisciplinary and Supportive Services for Patients With Head and Neck Cancer

D8 U: The other thing that I have found helpful is using staff like the speech, physical, and occupational therapists. The surgeon simply cannot do all of those jobs and does not have the expertise to do those jobs. So I try to get [all of these disciplines] involved very early.

Mr K: [Oral communication] is a significant issue. . . . I manage a group of employees and some of my employees are not co-located with me, so I have to talk to them by phone. Some of this is alleviated by modern communication and I can communicate with them by e-mail, for example. I am going to a speech and swallowing therapist. She’s given me certain exercises for my mouth, tongue, head, and neck. She gave me exercises to read aloud. I’m supposed to focus on pronouncing words and emphasizing certain syllables. She actually records video of my swallowing technique. I’m not sure what the device is called, but she runs a tube through my nose and down into my throat and records a video of how the swallowing looks. By studying that, she can then give me pointers as to how to improve my swallowing.

One of the fundamental principles of palliative care is that it is practiced within an interdisciplinary team, pooling the expertise of physicians, nurses, social workers, and chaplains to provide the best quality of care for patients and their families. For patients with head and neck cancer, this approach is key, but many other disciplines must be included to ensure optimal treatment and recovery for these patients. Although there is evidence that multidisciplinary palliative care teams improve outcomes for patients, no studies to date have examined their advantages in patients with head and neck cancers. In addition to otolaryngologist–head and neck surgeons and oncologists and radiation oncologists completing treatment, several other professionals play important roles. Dentists may create prostheses for the teeth or jaw if these are resected. Speech and language pathologists provide voice rehabilitation, including acoustic assistive devices, and teach patients modified swallowing techniques. They also work with families in meal preparation and in helping them to understand the effects of the disease and treatment. Physical therapists and occupational therapists help patients adapt to reconstructive procedures involving the use of flaps. Clinical social workers can help coordinate care across settings, nutritionists help assist patients obtain adequate nutrition and hydration, and ophthalmologists or neurosurgeons may be involved depending on the location of the cancer.

Early and regular contact between these members of the team is essential to ensure optimal care for patients with these malignancies. At our medical center, weekly meetings of the Multidisciplinary Program for Treatment of Diseases of the Head and Neck include otolaryngologists, oncologists, radiation oncologists, speech pathologists, social workers, and palliative care clinicians who discuss each patient who is to be admitted to the hospital to clarify the treatment plan and determine which services an individual patient will need. The palliative care nurse practitioners follow up ambulatory patients in the head and neck clinic to assess symptoms and help coordinate care. This approach to care improves patient satisfaction and ensures safe and efficient transitions across care settings, a key quality indicator for the health care of patients with complex disease. In addition, integrating palliative care into the care plan at an earlier point in the course of the patient’s disease process may help to reinforce, for both patients and clinicians, the idea that palliative care is not the same as end-of-life care. (For more information about staffing or sustaining a successful palliative care program, including solutions to common administrative and financial difficulties, go to http://www.capc.org.)

The team approach to care begins prior to surgery when a nutritionist and speech therapist provide patients with a series of pretreatment exercises that may improve swallowing and speech following surgery. Preoperative integrated care may also help patients develop expectations and reduce feelings of anxiety and helplessness.

The interdisciplinary team also provides support for patients and their families, as well as promotes self-care and relieving stress and burnout among clinicians caring for these patients with serious illness. Studies have shown that caring for patients with serious illness takes a toll on the health of caregivers, and the high recurrence rate, along with high symptom burden and physical changes caused by head and neck cancer and its treatments, create serial challenges for caregivers.
Care of the Dying Patient With Head and Neck Cancer

Because of the unique nature of malignancies of the head and neck, special consideration must be given to end-of-life care for these patients. As with all cancer patients, predicting when an individual is near the end of life can be difficult. Signs include being bed-bound, semicomatose, only able to take sips of fluid, and an inability to take oral medications or tolerate artificial hydration and nutrition. At this point, clear communication with patients (when possible) and families is important so they understand that the patient has begun to enter the last phase of life. Referral to an inpatient palliative care unit or home hospice program should be considered to ensure excellent management of symptoms and to provide the needed emotional and psychological support. Although artificial hydration and nutrition plays a role for patients earlier in the course of their disease, it may become burdensome near the end of life and lead to edema, nausea and vomiting, and pulmonary congestion. Thus, it may make patients more uncomfortable and serve to only prolong the dying process. As such, families should be educated about how this once beneficial treatment may now be a source of suffering and stopping it should be considered. Another management issue for many patients with advanced head and neck cancer is the “carotid blowout” syndrome—a process by which the cancer erodes into the carotid artery (or other great vessel in the neck) leading to exsanguination. This process may take place gradually, with occult blood loss into the surrounding tissues, or with rapid, massive blood loss from the neck. Although the prevalence of this dreaded complication is much rarer than in the past due to palliative surgical techniques, it can be frightening to both patients and their families. Patients with impending blowout should be managed in an inpatient setting, especially if children are present in the home. However, caregivers who understand the nature of this complication and wish to have the patient remain at home, as a practical issue, should keep dark towels (red or black) near the patient’s bedside to absorb the significant amount of blood that may be lost.

CONCLUSION

Palliative care is essential to the care of patients with head and neck cancer. These patients have unique physical symptoms and emotional needs relating to both the disease and its treatments. Including palliative care clinicians on the treating interdisciplinary team is a key element to improve care for patients with head and neck cancers, as well as for their family caregivers. As Mr K expressed, returning to a normal lifestyle is a goal patients and their families strive for and requires the expertise of a range of specialists to resume their lifestyle as much as possible. Ensuring that these patients—and their families—receive comprehensive supportive services can increase the likelihood that patients will be able to complete life-sustaining treatments and thus obtain the best possible outcomes and quality of life.

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Other Sources: For a list of relevant Web sites, see the article on the JAMA Web site at http://www.jama.com.

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Web Resources for Palliative Care for Patients With Head and Neck Cancer

CENTER TO ADVANCE PALLIATIVE CARE
http://www.capc.org

The Center to Advance Palliative Care (CAPC) provides health care professionals with the tools, training, and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings. Web resources include solutions to common administrative and financial difficulties encountered when creating and developing palliative care programs. A national organization, CAPC is dedicated to increasing the availability of quality palliative care services for people facing serious illness.

NATIONAL CANCER INSTITUTE PAGE FOR INFORMATION ABOUT HEAD AND NECK CANCER

Maintained by the National Cancer Institute, this page provides information about head and neck cancers, including information about diagnosis, treatment, and clinical trials.

NATIONAL COMPREHENSIVE CANCER NETWORK
http://www.nccn.org

This Web site provides guidelines for treatment of malignancies using the consensus process of national experts and review of relevant evidence from clinical trials. Specific information relating to malignancies of the head and neck can be found at http://www.nccn.org/professionals/physician_gls/PDF/head-and-neck.pdf

ORAL CANCER FOUNDATION
http://www.oralcancerfoundation.org

A national public service, this nonprofit entity is designed for prevention, education, research, advocacy, and support activities. It provides a patient-survivor forum that is open to the public where those currently fighting oral cancer can gain insights and support. This was founded by an oral cancer survivor. This site is recommended by the National Comprehensive Cancer Network and is supported by numerous pharmaceutical companies, including Bristol-Myers Squibb, Johnson & Johnson, Abbott, Introgen, and Colgate-Palmolive.

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER
http://www.spohnc.org

This Web site for patients was created by a patient with head and neck cancer. It includes general information, information about treatments, and links to support groups across the country. This site is recommended by the National Comprehensive Cancer Network and is supported by numerous pharmaceutical companies, including ALIGN, AstraZeneca, Bristol-Myers Squibb, ImClone, Laclede, and Sanofi-Aventis.