The Quality of Care Provided to Hospitalized Patients at the End of Life

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Background: Patients in American hospitals receive intensive medical treatments. However, when lifesaving treatments are unsuccessful, patients often die in the hospital with distressing symptoms while receiving burdensome care. Systematic measurement of the quality of care planning and symptom palliation is needed.

Methods: Medical records were abstracted using 16 Assessing Care of Vulnerable Elders quality indicators within the domains of end-of-life care and pain management designed to measure the quality of the dying experience for adult decedents (n=496) hospitalized for at least 3 days between April 2005 and April 2006 at a university medical center recognized for providing intensive care for the seriously ill.

Results: Over half of the patients (mean age, 62 years; 47% were women) were admitted to the hospital with end-stage disease, and 28% were 75 years or older. One-third of the patients required extubation from mechanical ventilation prior to death, and 15% died while receiving cardiopulmonary resuscitation. Overall, patients received recommended care for 70% of applicable indicators (range, 25%-100%). Goals of care were addressed in a timely fashion for patients admitted to the intensive care unit approximately half of the time, whereas pain assessments (94%) and treatments for pain (95%) and dyspnea (87%) were performed with fidelity. Follow-up for distressing symptoms was performed less well than initial assessment, and 29% of patients extubated in anticipation of death had documented dyspnea assessments.

Conclusion: A practical, medical chart–based assessment identified discrete deficiencies in care planning and symptom palliation that can be targeted to improve care for patients dying in the hospital.

Arch Intern Med. 2010;170(12):1057-1063

Patients in American hospitals receive intensive medical treatments.1,2 Given the aggressiveness of medical care provided to inpatients who are seriously ill and approaching death, it is not surprising that medical care provided during the last year of life accounts for 10% to 12% of the US health care budget and 27% of Medicare expenditures.3,4

Despite this intensive resource use, studies suggest that when lifesaving treatments are unsuccessful, hospitalized patients often die with distressing symptoms. Studies of patients who died in the hospital find that pain, dyspnea, and restlessness or agitation are prevalent before death.5-7 Furthermore, persons dying in the hospital often receive burdensome care immediately before death that may not match patient preferences. In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT),8,9 38% of patients spent at least 10 days in an intensive care unit (ICU) prior to death, and physicians commonly misunderstood patients’ resuscitation preferences. Interviews conducted with family members of a nationally representative sample of patients who died in the hospital revealed that half perceived inadequate physician contact and one-quarter reported concerns about physician communication during the hospitalization.10

Studies show that while many patients want high-intensity care aimed at improving survival and quality of life, when treatment fails, patients and families value other outcomes, including symptom control during the dying process. In one survey evaluation,11 many adults rated certain clinical outcomes (severe pain, severe stroke, dementia, permanent coma) as worse than death. In another study,12 patients were less likely to desire aggressive treatments if their outcome would be more impaired than their current health state. Patients also would prefer to die at home.13 Despite this, half of patients die in the hospital, and when patients are admitted to hospice they often are close to death.14,15

These data suggest that patient goals for medical care and careful weighing of the burdens and benefits of treatments in the light of clinical realities may not always
drive the care that seriously ill hospitalized patients receive. However, there has not been a systematic, clinically detailed measurement of the quality of care planning, palliation, and symptom management among dying inpatients. We applied quality indicators (QIs) from the Assessing Care of Vulnerable Elders (ACOVE) set to measure the quality of care provided to a decedent cohort at the University of California, Los Angeles, Medical Center, a quaternary care university hospital with 600 beds and a large transplant program, recognized for providing aggressive care toward the end of life to identify areas for quality improvement.16

**METHODS**

We used ACOVE QIs from the end-of-life care and pain management domains that were developed based on the scientific literature and expert consensus methods to evaluate the medical care delivered to all dying patients during their terminal hospitalization.17 Although these QIs were initially developed for vulnerable elders, we applied them to the entire decedent sample because these patients are also vulnerable and would benefit from the identified processes of care. Because all patients had died before study initiation, the investigation was exempt from institutional review board approval (G06-09-025-01 exemption).

**ACOVE END-OF-LIFE QUALITY INDICATORS**

The ACOVE QIs are evidence-based measures of process of care quality designed to cover the spectrum of care from prevention to treatment and follow-up for vulnerable older persons, including pain management and end-of-life care.17 The ACOVE set of measures contains 392 QIs covering 26 conditions and is designed primarily for medical record abstraction. In prior work, quality of care measured using these measures was linked with improved survival consistent with the Donabedian Quality of Care Framework.18,19 However, to our knowledge, the ACOVE QIs aimed at end-of-life care have not been implemented previously. Conceptually, these process measures link to improved outcomes of quality of death- and health-related quality of life rather than survival.20

Among the 29 QIs focused on end-of-life care and pain management, we selected all that could be measured using the inpatient medical record from a terminal hospitalization.21 This included 10 end-of-life and 2 pain indicators, as well as 1 added measure aimed at implantable cardioverter/defibrillator (ICD) use in the dying patient from a related set of QIs developed using identical methods.22 These 13 measures fit into 3 domains of end-of-life care: eliciting goals of care, pain assessment and management, and dyspnea assessment and management. Because 3 of these measures contain 2 discrete care processes, we describe care for 16 QIs (Table 1).

**DECEDENT SAMPLE**

A decedent sample was selected for this study because we were most interested in quality of care for patients who are very close to death or at high risk of dying. We identified all patients 18 years or older who died during admission to 1 medical center between April 2005 and April 2006 following a hospitalization for at least 3 days. Of 586 adults who died, 86 died less than 3 days after admission. Of the 500 adult decedents who died after 3 or more days, complete terminal hospitalization medical records were available for 496 (99%) who constituted the study sample.

**MEDICAL RECORD ABSTRACTION**

A medical record abstraction tool was developed to collect data describing patients and how they died in the hospital (ie, demographics, clinical characteristics, life-sustaining treatment decisions) and to collect data elements for the ACOVE end-of-life and pain management QIs. Information was obtained from the full medical record, including the hard-copy record, a partial electronic medical record, and a nursing electronic record. The abstraction instrument included a medical record abstraction tool, a companion tool containing detailed information on abstraction guidelines and skip patterns, a checklist to guide efficient abstraction, answers to frequently asked questions, and standard medication lists.

Experienced nurse abstractors were trained to use the abstraction tool following a previously used method, which includes intensive training, tandem abstraction and comparison, and reliable abstraction of 5 testing charts.23 Abstractors participated in bimonthly meetings with discussion of questions and updating of guidelines. Ten percent of medical records were randomly selected to be abstracted a second time by a different nurse. Reabstraction revealed that 92% of QIs were triggered identically (pooled $\kappa=0.67$) and scoring for identically triggered QIs had 90% agreement (pooled $\kappa=0.67$).24 In addition, nearly identical QI scores were obtained from the 47 sets of abstracted and reabstracted records ($r=0.96$).

**STATISTICAL ANALYSIS**

A patient who was eligible for a QI received a score of 1 for that indicator if they received the recommended care process; otherwise, they received a score of 0. For QIs that could be triggered multiple times for a given patient, a score between 0 and 1 was possible. The QIs measured whether advance care planning procedures were undertaken, whether patients participated, when possible, in care decisions, and the approach to pain and dyspnea. If the medical record indicated that the patient refused the care process, the QI was considered to be passed. We identified how many times each quality indicator was triggered in the patient sample and computed the pass rate for each QI by dividing the number of indicators that were passed by the number of eligible patients. We also calculated pass rates for the 3 QI domains (goals of care, pain, and dyspnea). Analyses were performed with SAS statistical software (version 9.1; SAS Inc, Cary, North Carolina).

**SENSITIVITY ANALYSES**

The ACOVE QIs were developed to be applied to a vulnerable sample of community-dwelling persons 65 years or older and patients 75 years or older.17,20 We applied these measures to a full inpatient decedent sample. To understand whether quality of care was related to the initial vulnerability of subgroups of dying patients, we studied patients 75 years or older compared with younger decedents, patients with and without “end-stage disease” on admission, and patients documented to have an ”expected death” at least 3 days before death compared with those without such documentation. We defined end-stage disease to include 1 or more of the following: advanced cancer, end-stage pulmonary disease, end-stage heart failure, end-stage liver disease, end-stage renal disease, AIDS, or end-stage dementia. We defined “expected death” as any physician documentation that the patient had a terminal illness or a grave prognosis, was receiving hospice care, had life-threatening disease, or was dying. For these analyses, we computed quality scores at the patient level and compared overall and domain quality of care scores using t tests between groups.
patients, an organ transplant was considered during the hospitalization: liver (17%), bone marrow (3%), heart (3%), and lung (2%). Eighty-five percent of patients had medical record documentation, suggesting that clinicians anticipated the death would likely occur during the hospitalization; 47% had a documented “expected death” 3 or more days before death (Table 2).

The patients had a median hospital length of stay of 15 days (mean, 24 days; range, 3-216 days) with 63% (n=312) hospitalized more than 10 days. Eighty-two percent of patients were admitted to the ICU with a median ICU stay of 3 or more days before death (Table 2).

Table 1. Quality Indicators for Patients Dying in the Hospital

<table>
<thead>
<tr>
<th>Domain</th>
<th>Quality Indicator</th>
<th>Eligible Patients, No.</th>
<th>Quality Indicators Passed, %</th>
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<tbody>
<tr>
<td>Goals of care</td>
<td>If a vulnerable elder is admitted to the hospital or nursing home, then within 48 h of admission the medical record should contain the name of the patient’s surrogate decision maker, or documentation of a discussion to identify/search for a surrogate decision maker. If a vulnerable elder with severe dementia is admitted to the hospital and survives 48 h, then within 48 h of admission, the medical record should document that the patient’s preferences for care have been considered or an attempt was made to identify them. If a vulnerable elder is admitted to the intensive care unit and survives 48 h, then within 48 h of intensive care unit admission, the medical record should document that the patient’s preferences for care have been considered or an attempt was made to identify them. If a hospitalized vulnerable elder requires mechanical ventilation (for &gt;48 h), then within 48 h of the initiation of mechanical ventilation, the medical record should document the goals of care and the patient’s preference for mechanical ventilation or why this information is not available. If a vulnerable elder with decision-making capacity has orders in the hospital or nursing home to withhold or withdraw a life-sustaining treatment (eg, a DNR order), then the medical record should document patient participation in the decision or why the patient did not participate. If a vulnerable elder has documented treatment preferences to withhold or withdraw life-sustaining treatment (eg, a DNR order, no tube feeding, no hospital transfer), then these treatment preferences should be followed. If a vulnerable elder with dementia has a gastrostomy or jejunostomy tube placed, then prior to placement, the medical record should document 1 of the following: patient preferences concerning tube feeding, or if the patient is decisionally incapacitated and a surrogate decision maker is available, discussion of patient preferences or best interests, or if the patient is decisionally incapacitated and a surrogate decision maker is NOT available, a formal decision mechanism should be used. If a patient is enrolled in hospice or dies an expected death and has an ICD in place at death, then the ICD should have been deactivated or the medical record should document why it was not deactivated.</td>
<td>496 82</td>
<td></td>
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<tr>
<td>Pain</td>
<td>If a hospitalized vulnerable elder has a new complaint of moderate or severe pain, then the medical record should indicate that an intervention and follow-up assessment of the pain occurred within 4 h. Interventions: analgesia, sedation, or pain-informed care. Follow-up assessment: the medical record should contain documentation about presence or absence of pain during the last 7 days of life. If a vulnerable elder with chronic pain is treated with opioids, then the patient should be offered one of the following: a stool softener, a laxative, increased fiber, or stool-softening foods, or the medical record should document the potential for constipation and/or explain why the bowel regimen is not needed. If a vulnerable elder who was conscious during the last 7 days of life died an expected death, then the medical record should contain documentation about presence or absence of pain during the last 7 days of life.</td>
<td>1804 67</td>
<td></td>
</tr>
<tr>
<td>Dyspnea</td>
<td>If a vulnerable elder who had dyspnea in the last 7 days of life died an expected death, then the medical chart should document dyspnea care and follow-up. Treatments: oxygen, noninvasive positive pressure ventilation; if a noncomatose vulnerable elder is not expected to survive and a mechanical ventilator is withdrawn or withheld, then the medical chart should document whether the patient has dyspnea and the patient should receive (or have orders available for) an opiate/benzodiazepine/barbiturate infusion. Assessment: the medical record should document the goals of care and the patient’s preference for mechanical ventilation or why this information is not available.</td>
<td>950 76</td>
<td></td>
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<tr>
<td>Overall quality of care</td>
<td></td>
<td>3086 70</td>
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Abbreviations: DNR, do not resuscitate; ICD, implantable cardioverter/defibrillator.

RESULTS

The analytic sample of 496 decedents had a mean age of 62 years; 47% were women, 62% were white non-Hispanic, and 60% were married. Nearly three-quarters of the patients were admitted to the hospital with end-stage disease or were 75 years or older. Forty-five percent of the sample had private insurance as their primary source of payment, and 41% had Medicare. Twenty-one percent of the decedents had advanced cancer; 16%, end-stage liver disease; 11%, end-stage pulmonary disease; 9%, end-stage renal disease; 6%, end-stage heart failure; and 1%, severe dementia on admission to the hospital. In one-quarter of the
Sixty-three percent of patients were visited by a chaplain during the terminal hospitalization. At least 1 family meeting was documented for 55% of patients. Seven percent of patients had a palliative care consultation, and 7% had an ethics consultation.

Quality of End-of-Life Care

The 496 patients triggered 3086 QIs, of which 2174 were passed (70%; QI range, 25%-100%). Patients were eligible, on average, for 6.2 QIs (range, 1-13 QIs). By domain, the mean quality score for goals of care was 67%; for pain care, 76%; and for dyspnea care, 71% (Table 1).

Goals of Care

Among the goals-of-care QIs, patients’ documented preferences for care related to resuscitation status and gas-
tric tube placement were respected with fidelity. Medical record documentation concerning a surrogate decision maker (or a reason why this could not be specified) was completed within 48 hours of admission 82% of the time. However, timely documentation of discussion about patient preferences on admission to the ICU or for those receiving mechanical ventilation occurred less than half of the time. While the presence of an advance directive documenting patient preferences would have satisfied this QI, only 18% of patients had an advance directive in their medical record at any point during hospitalization. For patients with cognitive ability, participation in decisions regarding life-sustaining treatment, or documentation about why this was not possible or desirable, was absent for more than half of patients. Patients with ICDs who were expected to die had documentation regarding deactivation of the device only 25% of the time.

Pain Care

As might be expected given an electronic nursing documentation record that elicited responses concerning pain, pain assessment and management were performed consistently with pass rates exceeding 80%. However, only 61% of patients receiving opioid medications had a bowel regimen prescribed or a reason documented why it was not.

Dyspnea Care

Although dyspnea treatments were almost always prescribed for patients undergoing withdrawal of a ventilator and expecting death, only 29% of these patients had dyspnea assessments documented. Most patients had dyspnea care for moderate to severe dyspnea documented during the last 3 days of life (87%); however, follow-up to ensure that treatments were effective occurred less often (70%).

SENSITIVITY ANALYSES

Overall, patients 75 years or older received slightly higher quality care than younger patients (73% vs 69%; P = .03). Older patients received better care for goals-of-care QIs (77% vs 65%; P = .001), but worse care for pain (65% vs 73%; P = .08) and dyspnea (67% vs 83%; P = .054). Overall quality scores did not differ between patients who had end-stage disease on admission and those who did not (70% vs 70%; P = .75), and domain scores also were similar. Patients with documentation of an expected death 3 or more days before death received similar quality of care compared with patients without such medical chart documentation, overall (70% vs 69%; P = .61) and in the goals-of-care domain (67% vs 70%; P = .31), but patients with expected death documentation received better quality pain care (76% vs 65%; P = .001) (Table 4).

Although the role of advance care planning remains an active topic within the current health care reform discussion, no controversy has been articulated about the importance of meeting minimal standards of quality of care for all dying patients. This application of QIs for end-of-life care to a full cohort of patients dying at a quaternary medical center demonstrated that while many areas of measured care are good, key aspects of care need improvement. The studied hospital is recognized both for intensive utilization at the end of life and positive outcomes among seriously ill patients.16,27-29 This evaluation reveals that most patients dying in the hospital are admitted with end-stage disease, and most spend time in the ICU with mechanical ventilation. Four in 10 had a decision for ventilation or hemodialysis to be withdrawn in order to permit death, and all but a few had life-sustaining treatment withheld or withdrawn. Thus, in order to die in the studied hospital, it was usually necessary for clinicians and families to make an explicit decision to aim toward less than fully aggressive care. This is an important message for both clinicians (who need to anticipate these decisions and initiate discussions) and policymakers. It also highlights the importance of the identified deficits in goals-of-care quality.

The most striking area in need of quality improvement is communication between physicians and patients (or their families) as they initiate intensive treatments. Even after 48 hours in the ICU or on the ventilator, more than half of patients had no medical record documentation about goals of care or an attempt to pursue the topic. Although medical care should be tailored to achieve patient’s goals and prior work shows that patients’ preferences depend on prognosis,11,30-32 medical care cannot be guided by informed choices absent communication about current clinical status and what course is likely to follow. The SUPPORT showed that physicians are often unaware of patients’ pref-

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<th>Table 4. Relationship of Mean Quality of End-of-Life Care According to Several Patient Characteristics</th>
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<td>Patient Characteristic</td>
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<tr>
<td>------------------------</td>
</tr>
<tr>
<td>Age ≥75 y</td>
</tr>
<tr>
<td>Age &lt;75 y</td>
</tr>
<tr>
<td>End-stage disease on admission</td>
</tr>
<tr>
<td>No end-stage disease on admission</td>
</tr>
<tr>
<td>Expected death documented</td>
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<td>No expected death documented</td>
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Abbreviation: NA, not applicable.

* P < .05 for comparison between patients 75 years or older and those younger than 75 years and for comparison between patients who died an expected death vs those who did not.

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end-of-life care is associated with important

communication concerns in the ICU setting, where prognosis can change rapidly. Among patients with cancer, communication regarding end-of-life care is associated with important

cortical functions. Among patients with cancer, communication concerning end-of-life care is associated with important

of patients for whom there was timely documentation regarding a surrogate decision maker should not be considered adequate; in this population, such communication and documentation should occur for every patient.

Although quality scores were high among the pain care indicators, it is important to recognize the low bar represented by these QIs. For example, nearly all patients received an intervention and follow-up for a complaint of loud noises or preferences. However, passing the measure did not require that the intervention mitigate the pain. Pain assessments prior to death were rarely lacking, most likely because standardized rating systems for pain assessments facilitate the documentation of pain. In contrast, dyspnea assessments were difficult to identify and capture in the medical records. More standardized assessments for symptoms other than pain may result in better process of care.

Palliative care and ethics consultations and— to a degree —family meetings occurred relatively infrequently given the vulnerable patient population. These interventions have been associated with improved outcomes for patients at the end of life and their caregivers, as well as increased provision and capture in the medical records. More standardized assessments for symptoms other than pain may result in better process of care.

This study has several important limitations. Most important, we evaluated a decedent sample, which may overestimate the level of attention afforded goals of care and symptom assessment among seriously ill inpatients with the potential to die; patients who recover to leave the hospital may be less likely to receive attention to goals and symptoms, although such care processes are important for those individuals as well. This is supported by our sensitivity analysis of patients who were expected to die compared with those who were not. Overall quality scores were similar, but patients who died an expected death received higher quality care for pain. Exploration of quality of care is needed for a cohort of severely ill patients who do not die in the hospital, including those who enter hospice care. Furthermore, it should be noted that these QIs were developed for vulnerable elders and persons 75 years or older. Patients 75 years or older received better care for goals-of-care measures compared with younger patients, but pain and dyspnea care was not significantly different. While early specification of a surrogate decision maker might not be necessary for younger patients admitted to the hospital, preference documentation for patients receiving intensive care and incorporation of preferences into care decisions should be applicable across the age spectrum. In addition, there was no difference in quality of care between patients admitted with end-stage disease and those without such conditions. This suggests that the deficits in care demonstrated in this analysis reflect general practice patterns rather than clinician response to individual patient preferences or goals. However, we evaluated only 16 care processes; additional areas of evaluation, such as other symptoms (ie, nausea, anxiety), and social and spiritual domains, including caregiver support, should be targeted in future work.

This evaluation was undertaken only at a single medical center and needs to be repeated in other venues. This analysis demonstrates the feasibility of this quality of care evaluation; the tools for medical record abstraction are available for others to apply. The medical records evaluated reflect care provided 3 to 4 years ago; practice patterns may have changed. For example, the institution's palliative care service has increased its visibility in the interim and care may have already improved. The findings may not be applicable to community hospitals or academic centers in other regions, but this is an empirical question. Moreover, medical record documentation does not perfectly reflect provision of care, however, the quality indicator development process explicitly considered this issue, and prior work has shown that documentation deficiencies were themselves indicative of poor quality of care. It is important to note that we found data on dyspnea particularly difficult to abstract from the medical record. To ensure that we accurately captured quality of care, we performed a supplementary physician implicit medical chart review that confirmed the lack of documented dyspnea assessment after ventilator withdrawal.

Driven in part by recognition of intensive treatments for seriously ill patients, this rigorous quality of care assessment was undertaken by an academic medical center to better understand the quality of care provided to dying patients. Deficits in communication, dyspnea assessment, ICD deactivation, and bowel regimens for patients prescribed opioids should be targeted for quality improvement. The findings suggest much room for improvement in treating patients dying in the hospital.

Accepted for Publication: December 29, 2009.

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Author Contributions: Dr Walling had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: Walling, Lorenz, Roth, and Wenger. Acquisition of data: Walling, Roth, Barry, and Wenger. Analysis and interpretation of data: Walling, Asch, Lorenz, Roth, Kahn, and Wenger. Drafting of the manuscript: Walling and Wenger. Critical revision of the manuscript for important intellectual content: Walling, Asch, Lorenz, Roth, Barry, and Wenger. Statistical analysis: Walling. Obtained funding: Lorenz and Wenger. Administrative, technical, and material support: Walling, Lorenz, Roth, and Barry. Study supervision: Asch, Lorenz, Kahn, and Wenger.
Financial Disclosure: None reported.

Funding/Support: This project was supported by a donation from Mary Kay Farley to RAND Health. Dr Waller was supported by National Research Service Award Training Grant T32 PE19001, the UCLA Specialty Training and Advanced Research Program, and the NIH Loan Repayment Program.

Role of the Sponsor: The funding source had no role in the design, execution, analysis, or interpretation of the study or in the decision to submit the results for publication.

Previous Presentation: Preliminary data were presented at the Society of General Internal Medicine Annual National Meeting; May 14, 2009; Miami, Florida, and received a Geriatric Abstract Award.

Additional Contributions: Robert H. Brook, MD, ScD, J. Thomas Rosenthal, MD, and Thomas E. Sibert, MD, MBA, provided guidance to the project. Myrtle C. Yamamoto, RN, BSN, expertly led the team of nurse abstractors, including Linda S. Oshinomi, RN, BSN, Angelica Padua-Laus, RN, RN, Nancy Larkin, RN, BSN, and Anna M. Dickey, RN, BSN. Ron D. Hays, PhD, Robert M. Kaplan, PhD, and Martin Shapiro, MD, PhD, provided valuable advice. Caren Kamberg, MSPH, was the project manager, and Patricia Smith, Jenny Kotlerman, MS, Mark Lucas, BA, and Victor Gonzalez, BA, provided technical assistance. We thank Mrs Mary Kay Farley for her support and encouragement.

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