Evidence-Based Recommendations for Information and Care Planning in Cancer Care

Anne Walling, Karl A. Lorenz, Sydney M. Dy, Arash Naeim, Homayoon Sanati, Steven M. Asch, and Neil S. Wenger

ABSTRACT

The practice of oncology is characterized by challenging communication tasks that make it difficult to ensure optimal physician-patient information sharing and care planning. Discussions of diagnosis, prognosis, and patient goals are essential processes that inform decisions. However, data suggest that there are deficiencies in this area. We conducted a systematic review to identify the evidence supporting high-quality clinical practices for information and care planning in the context of cancer care as part of the RAND Cancer Quality—Assessing Symptoms, Side Effects, and Indicators of Supportive Treatment Project. Domains of information and care planning that are important for high-quality cancer care include integration of palliation into cancer care, advance care planning, sentinel events as markers for the need to readdress a patient’s goals of care, and continuity of care planning. The standards presented here for information and care planning in cancer care should be incorporated into care pathways and should become the expectation rather than the exception.

INTRODUCTION

Cancer is an emotionally laden, often disruptive, and sometimes tumultuous experience for patients, families, and providers. Good communication with an emphasis on anticipatory planning is an essential aspect of good oncology care. A number of critical processes are implicit in good cancer care communication. Discussions of diagnosis, prognosis, and treatment decisions and deciding who to include in the discussions are essential processes that inform decision making.1-4 Most patients desire to participate in decisions regarding their own treatment.5-7 Timing of these steps is another critical issue, and although perhaps reluctant to raise these issues themselves, most cancer patients want to discuss these issues when the oncologist feels it is necessary.8

Earlier efforts to improve cancer care communication emphasized advance directives, or written legal documentation addressing resuscitation preferences; however, more recent efforts emphasize advance care planning (ACP). Legal standards, clinical guidelines, and ethical consensus support ACP as a key aspect of excellent supportive care.9,10 ACP is a broad construct that emphasizes the steps required to facilitate patients to guide their future care including the specification of surrogate decision makers. The broad goal is to bring together patients, caregivers, and providers to develop a coherent care plan that meets the patient’s goals, values, and preferences. Because delirium and other forms of cognitive impairment are prevalent during treatment and as malignancies advance, identifying and engaging a surrogate in the process of ACP is especially important.11-14

Good quality communication and ACP commonly do not occur for reasons related to physicians, patients, and the practice environment. An example is telling a patient bad news. Many physicians have difficulty transmitting bad news.15,16 Although understanding prognosis is essential to making informed decisions about cancer therapy, physicians may be concerned about engendering despair in patients and thus avoid explicit discussion of a poor prognosis.17-19 Although it is generally accepted that accurate prognostication is helpful in the care of oncology patients, physicians do not always have accurate prognostic information or adequate prognostic tools, and prognosis is rarely documented in the medical record.20-25 In addition, cancer patients often do not feel comfortable addressing their concerns in a clinical encounter, and such issues often remain unexplored.26-28 There is also lack of evidence regarding appropriate timing of discussion with oncology patients about difficult future treatment options, and best practice is currently based mostly on qualitative studies.27-29
Time constraints during the clinical encounter may distract physicians or impede initiation of conversations in areas that tend to be difficult to discuss. Ideal communication strategies have been delineated by experts that emphasize the need to be sensitive to patients’ perspective concerning their cancer and to continually address their need for information, support, and involvement in the care plan. Such patient-centered communication approaches are time intensive, and limited data suggest that they are often absent in current clinical practice.

The importance of assuring communication that facilitates ACP is underscored by evidence that the aggressiveness of cancer treatments, even among patients with a poor prognosis, continues to increase. Medicare claims from patients with malignancy showed that the percentage of patients receiving chemotherapy within 2 weeks of death increased from 13.8% in 1993 to 18.5% in 1996, and there were similar increases in hospitalizations, emergency room visits, and intensive care unit stays. Yet, it is unknown whether this reflects increased desire for aggressive care at end of life. Among 335 decedents with breast cancer, 2 months before death, 64% of patients continued to receive endocrine therapy, and 20% received chemotherapy. Although patients often continue to receive aggressive cancer care toward the end of life, it seems that efforts at palliation are not aggressively pursued. The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment showed that, among patients with colon and non–small-cell lung cancer, approximately 28% of patients suffered from confusion in the last 3 days of life and 40% were in serious pain during the last 3 days of life despite the fact that more than 65% of these patients had a preference for comfort care in the last 3 days to 1 month of life. Of the patients in this study with lung and colon cancer who had a preference to focus on comfort-oriented care in the last 3 days of life, one in 10 received care that was incongruent with their preferences as reported by family members.

We undertook a project to define quality standards for communication and ACP in cancer. We attempted to define the research evidence, clinical expertise, and consensus about ethical practice that would support a minimum set of practices required as a part of good care. This article presents our review of the literature that supports the need for oncology practice to routinely address integration of palliation with cancer care, ACP, sentinel events as a marker for the need to readdress a patient’s goals of care, and continuity of care planning.

We conducted a systematic review to identify the evidence supporting high-quality clinical practices for supportive cancer care as part of the RAND Cancer Quality—Assessing Symptoms, Side Effects, and Indicators of Supportive Treatment Project (Lorenz et al, submitted for publication). A five-clinician team including experts in oncology, palliative medicine, and ethics prioritized symptoms related to cancer, treatment-related toxicities, and information and care planning needs for quality indicator development. Information and care planning was identified as a priority because of its likely impact on patient and family care decisions and quality of life. The Assessing Symptoms, Side Effects, and Indicators of Supportive Treatment Project addressed the minimum standard of care for information and care planning consistent with quality supportive cancer care.

This report describes the evidence related to quality indicators for information and care planning that were regarded as valid and feasible by an expert panel. Articles were identified through MEDLINE, the Cochrane Database of Systematic Reviews, Cochrane Database of Abstracts of Reviews of Effects, and the Cochrane Register of Clinical Trials (1996 to 2006). We limited searches to English language, using terms combined with each topic area (Appendix, online only). To enrich the 10-year literature review, we searched for earlier citations selectively. We searched broadly and later included studies that included patients other than oncology patients because there are few formal trials of ACP specific to oncology. It is also important to note that much of the information underlying excellent practice in this area is theoretical literature based on ethical and professional principles rather than empirical experience.

In addition, we also evaluated relevant material from previous systematic reviews; we evaluated guidelines and quality indicators published after 2004 using the National Guideline Clearinghouse, National Quality Measures Clearinghouse, and Web sites of professional societies, medical organizations, and patient advocacy groups. Google searches made use of key words related to potential indicator topics.

Cancer patients often receive aggressive care toward the end of life despite the fact that many could benefit from more comfort-oriented care. Comprehensive treatment of cancer patients is broader than simply offering the next available aggressive treatment. The National Comprehensive Cancer Network and the National Consensus Project for Quality Cancer Care guidelines indicate that providing comprehensive multidisciplinary care should address pain and other symptoms, spiritual or existential concerns, caregiver burdens, and ACP.

A recent review of 18 studies regarding patient preferences for venue of death for the general population or groups containing cancer patients concluded that home and hospice care were the most desirable end-of-life locations. Qualitative studies and nationally representative surveys of patients and caregivers highlight the importance of addressing pain and symptom management, communication of care plan, financial issues, caregiver support, and preparation for death.

The palliative care team in the form of inpatient palliation or community hospice can provide supplemental components to round out comprehensive cancer care. A systematic review by Higginson et al of studies through 1999 evaluating the effectiveness of hospice and palliative care teams looked at 44 studies including five systematic reviews with 30 randomized controlled trials (RCTs) and four additional RCTs (22 home based, nine hospital based, four combining home and hospital, three inpatient units, and six home hospice/hospital). A considerable proportion of patients in these studies had cancer. Significant improvement in pain and other symptoms was observed in patients receiving palliative care interventions compared with usual care. The standardized mean difference in pain scores was 0.41 (95% CI, 0.11 to 0.63) in favor of palliative care teams reducing pain. Note that a standardized mean difference in the range of 0.2 to 0.5 is considered a medium effect. This review also found that palliative care teams were effective at improving patient, but not caregiver, outcomes.

We identified an additional RCT of outpatient palliative consultation for a clinically heterogeneous group of patients that included cancer patients. Using validated measures, the investigators found that multidisciplinary specialty palliative care management working in...
concert with primary care providers was effective in improving dyspnea, anxiety, sleep quality, and spiritual well-being but not pain or depression.43 Recently, an RCT evaluated an in-home palliative care intervention with a multidisciplinary team for homebound, terminally ill patients (47% cancer patients). This study of 298 patients showed that the intervention group had greater satisfaction, were more likely to die at home, and were less likely to visit the emergency room.44

Given this preponderance of evidence, patients should have a comprehensive palliative assessment addressed within their cancer care. Experts agree that, when death becomes expected, a patient should receive palliative care in some form and important issues to address include pain and other symptoms, spiritual or existential concerns, caregiver burdens, and financial concerns. Although it is possible to cover these issues solely in the context of primary care, the evidence suggests that palliative care and hospice teams are particularly skillful in this area, especially as cancer advances; their input should be elicited routinely in most cancer patients’ courses, particularly when cure is no longer an option (Table 1).

END-OF-LIFE DISCUSSION AND ACP

ACP provides a method for effective and empathetic patient-centered communication regarding a terminal diagnosis, including prognosis and care plans. Much literature supports the importance of attention to these issues,1-7 but one study suggests that patients, families, and providers vary on the emphasis they place on these matters. Steinhauser et al27 surveyed 332 bereaved family members, 340 seriously ill patients including cancer patients, 361 physicians, and 429 other care providers and found that, although all four groups agreed on important issues such as pain management and preparation for death, physicians and care providers did not give the same level of value to other issues such as mental awareness at end of life. This study demonstrated that anticipatory planning is important because all groups agreed that end-of-life care was important, but it also highlighted the fact that a physician or care provider may not know what is important for an individual patient at end of life. For example, 92% of patients surveyed felt that it was very important to be mentally aware at end of life, and only 65% of physicians felt that this was very important. In addition, 88% of physicians and 95% of other care providers agreed that patients should discuss personal fears about end of life, but only 61% of patients agreed with this.37

Communication about the issue of prognosis is an essential aspect of effective ACP, and yet, communication of prognosis is infrequently documented, and when physicians do transmit prognostic guesses, these are systematically overestimated.45 A study that looked at inpatients with cancer in a retrospective chart review showed that documentation of prognosis was found only 38% of the time and that a patient had 2.2 times the odds of having a Do Not Resuscitate order if there was a documented discussions of prognosis.22 Of course, communication about prognosis must be individualized. In addition

### Table 1. Recommendations for Information and Care Planning in Cancer Patients

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Evidence</th>
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<tbody>
<tr>
<td><strong>Assess comprehensively from a palliative perspective and document pain and other symptoms, spiritual or existential concerns, caregiver burdens/need for practical assistance, and financial concerns for patients with advanced cancer when death is expected</strong></td>
<td>III</td>
</tr>
<tr>
<td><strong>Refer outpatients with advanced cancer for palliative care and/or hospice within 6 months of their death</strong></td>
<td>II</td>
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<tr>
<td><strong>Discuss prognosis and advance care planning within 1 month of a patient’s new diagnosis of advanced cancer</strong></td>
<td>II</td>
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<tr>
<td><strong>Document advance directive or surrogate decision maker in patients with advanced cancer when death is expected</strong></td>
<td>II</td>
</tr>
<tr>
<td><strong>Document patient’s goals or preferences for care in patients with advanced cancer within 48 hours of any admission to a hospital</strong></td>
<td>III</td>
</tr>
<tr>
<td><strong>Document patient’s goals or preferences for care in patients with advanced cancer within 48 hours of admission to an intensive care unit and before mechanical ventilation</strong></td>
<td>III</td>
</tr>
<tr>
<td><strong>Discuss prognosis and advance care planning with patients who have advanced cancer who have a new diagnosis of CNS metastases or who are to begin a new chemotherapy regimen</strong></td>
<td>II</td>
</tr>
<tr>
<td><strong>Discuss advance care planning with patients with advanced cancer who are to begin high-dose opiates</strong></td>
<td>II</td>
</tr>
<tr>
<td><strong>Discuss goals of care and preferences for interventions when a patient with advanced cancer undergoes new hemodialysis, pacemaker, or implantable cardioverter-defibrillator placement; major surgery; or gastric tube placement</strong></td>
<td>II</td>
</tr>
<tr>
<td><strong>Transfer advance directives with patients when they change venues</strong></td>
<td>II</td>
</tr>
</tbody>
</table>

**NOTE.** These recommendations are some of the standards addressed in the Assessing Symptoms, Side Effects, and Indicators of Supportive Treatment Project quality indicators for information and care planning in cancer patients.

1 Level I: randomized clinical trials; level II: nonrandomized controlled trials, cohort or case analysis, or multiple time series; level III: textbooks, opinions, and descriptive studies.

2 Guidelines sources include National Comprehensive Cancer Network, American Society of Clinical Oncology, Hastings Center, and National Consensus Project for Quality Cancer Care Guidelines. Guidelines may not be exactly matched with the recommendations, but Yes means that the spirit of one or more guidelines is captured in the recommendation.

3 Panelists reviewed supporting evidence and rated validity and feasibility (for obtaining information from medical records) for each recommendation. A Yes in the column means that the expert panel agreed with the recommendation.

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facilitate this process.

50,51 Experts agree that ACP is valuable and that flux over the course of illness, so it is important and appropriate to should take place, there is evidence that patients’ concerns are in minimal standards for when ACP should be discussed in cancer patients include at diagnosis of cancer, before an expected death to individual preferences, there are cultural differences in how this information should be communicated.46

Once a patient is aware of his or her prognosis, clinicians can begin to understand how patients will deal with this information and how their life goals will affect treatment decisions.47 Ideal communication strategies have been delineated by experts and include a variety of key processes. Two recently published communication strategies are described in Table 2.

On the basis of law, guidelines, and ethical consensus, a cancer patient’s goals and values should guide treatment and life-sustaining care decisions.9,10,47-49 These communication strategies emphasize the need to be sensitive to the patient’s perspective regarding cancer and to continually address the patient’s need for information, support, and involvement in the care plan.9,10,47-49 ACP provides a structure to facilitate this process.

Although there is lack of good evidence regarding when ACP should take place, there is evidence that patients’ concerns are in flux over the course of illness, so it is important and appropriate to readress them.46,51 Experts agree that ACP is valuable and that minimal standards for when ACP should be discussed in cancer patients include at diagnosis of cancer, before an expected death from cancer, and other sentinel events discussed in the following section (Table 1). Some available resources to help with ACP are listed in Table 3.

Table 2. Examples of Communication Strategies

<table>
<thead>
<tr>
<th>Reference</th>
<th>Strategy</th>
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<tbody>
<tr>
<td>Baile et al47</td>
<td>1. Facilitate the establishment of a close report with the patient</td>
</tr>
<tr>
<td></td>
<td>2. Identify the patient’s information preferences</td>
</tr>
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<td></td>
<td>3. Ensure comprehension of key knowledge and information</td>
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<tr>
<td></td>
<td>4. Address the patient’s emotions in a supportive fashion</td>
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<tr>
<td></td>
<td>5. Elicit the patient’s key concerns</td>
</tr>
<tr>
<td></td>
<td>6. Involve the patient in the treatment plan</td>
</tr>
<tr>
<td>Back et al50</td>
<td>Known as SPIKES:</td>
</tr>
<tr>
<td></td>
<td>S = Setup</td>
</tr>
<tr>
<td></td>
<td>P = Perception</td>
</tr>
<tr>
<td></td>
<td>I = Invitation</td>
</tr>
<tr>
<td></td>
<td>K = Knowledge</td>
</tr>
<tr>
<td></td>
<td>E = Empathize</td>
</tr>
<tr>
<td></td>
<td>S = Summarize and Strategize</td>
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</table>

Table 3. Some Available Advance Care Planning Resources

<table>
<thead>
<tr>
<th>Source</th>
<th>Web Site*</th>
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<tbody>
<tr>
<td>Aging With Dignity</td>
<td><a href="http://www.agingwithdignity.org/Swishes.html">http://www.agingwithdignity.org/Swishes.html</a>; see Five Wishes</td>
</tr>
<tr>
<td>American Bar Association</td>
<td><a href="http://www.abanet.org/aging/">http://www.abanet.org/aging/</a>; see The Consumer’s Tool kit for Healthcare Advance Planning</td>
</tr>
<tr>
<td>American Medical Association</td>
<td><a href="http://www.ama-assn.org/ama/pub/category/14894.html">http://www.ama-assn.org/ama/pub/category/14894.html</a>; see American Medical Association Web site under Ethics</td>
</tr>
<tr>
<td>Brigham and Woman’s Hospital: Center for Bioethics</td>
<td><a href="http://www.b">http://www.b</a> Brigham and Women’s Hospital: Center for Bioethics org.ethics/resourcesACP.aspx; see Advance Care Planning Resources</td>
</tr>
<tr>
<td>Caring Connections (from the National Hospice and Palliative Care</td>
<td><a href="http://www.caringinfo.org/PlanningAhead.htm">http://www.caringinfo.org/PlanningAhead.htm</a>; see Advance Directive and Advanced Care Planning; can get forms by state</td>
</tr>
<tr>
<td>EndLink: Resource for End of Life Education (from the Robert H. Lurie Comprehensive Cancer Center of Northwestern University)</td>
<td><a href="http://endlink.lurie.northwestern.edu/index.cfm">http://endlink.lurie.northwestern.edu/index.cfm</a>; see section on Advance Care Planning</td>
</tr>
<tr>
<td>National Association of Social Workers</td>
<td><a href="http://www.helpstartshere.org/Home.html">http://www.helpstartshere.org/Home.html</a>; perform search for: advance care planning-resources</td>
</tr>
</tbody>
</table>

*SAll Web sites were accessed April 20, 2008.

In addition to at the time of diagnosis and before an expected death, there are certain sentinel events in the disease process that should trigger goal-oriented discussions. It is possible that even a patient who wanted aggressive care at the onset of cancer care may change his or her mind as circumstances change.11,33 An interview study of 342 patients, including some terminal cancer patients, showed that, when advance directives were discussed, more participants chose to forgo more invasive long-term treatments (such as long-term mechanical ventilation, long-term feeding tubes, and long-term dialysis) as opposed to less invasive, short-term treatments (such as antibiotics and short-term mechanical ventilation).52 Cancer patients’ treatment preferences at the end of life differ from other groups. Thus, common aggressiveness of care should not be generalized from an overall patient population; it is important to address personal preferences concerning any invasive procedure.8 One study showed that older patients with metastatic cancer preferred artificial tube feeding to a lesser extent than was physicians’ practice.53 Another study prospectively evaluated the use of acute hemodialysis among hospitalized patients and found that having a cancer diagnosis was associated with dialysis being withheld rather than withdrawn.54

After the diagnosis of cancer, sentinel events that occur during the disease trajectory, such as initiation of invasive procedures, first diagnosis of CNS disease, and initiation of a new chemotherapy regimen, are important opportunities to readdress a patient’s goals given changes in prognosis and increased risk for being in a state in which the patient will not be able to make treatment decisions. A special challenge in ACP for cancer is the issue of how to address situations where a person lacks capacity. If a cancer patient has the capacity to make decisions about end-of-life care, he or she should do so.4,49,55 However, because delirium is so common in advanced cancer, patients are often unable to make decisions for themselves...
at the end of life. Theoretically, by assessing and documenting prognosis, ACP, and goals of care throughout the disease trajectory, informed decisions can be made, desired care can be received, and unwanted aggressive care can be avoided.

Experts agree that the following sentinel events in cancer care should herald times that ACP should be addressed if they have not already been discussed: admission to an intensive care unit, initiation of mechanical ventilation, diagnosis of CNS metastasis, initiation of a chemotherapy regimen, initiation of new hemodialysis, pacemaker or implantable cardioverter-defibrillator placement, decision to undergo major surgery, and a decision for gastric tube placement (Table 1).

### ACP: IMPROVING LOW RATES THROUGH PALLIATIVE CARE TECHNIQUES

Ideally, for patients approaching the end of life, a surrogate decision maker has been identified, and ACP has occurred. Unfortunately, advance directives are not always completed, and provided care is often inconsistent with patient preferences. A study in a tertiary care cancer hospital showed that only 27% of critically ill cancer patients had completed an advance directive, and 16 observational studies evaluated in a systematic review by Shalowitz et al showed patient-surrogate agreement to be only 68%.

However, several studies have shown that a variety of interventions can increase documentation of advance directives. A systematic review by Guo and Harstall found six RCTs that used patient-physician communication techniques to improve frequency of advance directive completion. Hanson et al conducted a systematic review that evaluated 16 studies, seven of which were RCTs, and concluded that educational interventions for physicians were challenging but increased the ability of physicians to elicit patient preferences; three studies found that this approach reduced the use of life-sustaining treatments, but no intervention had an effect on pain, suffering, or the cost of care. A more recent RCT by Engelhardt et al used a palliative care/coordinated care intervention that improved completion of advance directives (69% vs 48% for patients received usual care; \( P = .006 \)). In addition, two recent RCTs showed increased patient-surrogate congruence in goals of care with a communication and care planning intervention.

Despite the fact that some studies of ACP have suggested little effect on end-of-life decision making, other ACP interventions—many times as one component of a palliative care intervention to effect hospice enrollment—showed positive effects on patient satisfaction, patient knowledge, and psychological adjustment. Many authors conclude that these types of palliative care approaches, which have been shown to increase the documentation of goals of care and increase the likelihood of following a patient’s wishes at the end of life, should be encouraged. Oncologists should be open with patients about prognosis and be comfortable addressing sensitive issues such as future goals of care in the context of their patient’s disease, especially when it is essential for the information to be given so that important decisions can be made (Table 1).

### CONTINUITY

If patients and clinicians make the effort to complete an advance directive in the process of ACP, this information should be available to inform later care. However, observational studies suggest that advance directives are not as effective as they could be if they are not documented effectively or not communicated between patients, providers, and venues. A study by Virmani et al, in which seriously ill cancer patients and their physicians were interviewed regarding various aspects of advance directives, showed that physicians were frequently unaware of their patients’ advance directives. A prospective study by Danis et al of nursing home residents showed that, when advance directives were placed in the medical chart, a later evaluation of outcome events revealed that care was inconsistent with advance directives 25% of the time.

Laws and regulations can create structures that facilitate transportability of preferences across venues. State-level work in Oregon and other states and regions suggests that improvements can be made with communicating Do Not Resuscitate orders and other end-of-life treatment preferences. Oregon developed Physician Orders for Life-Sustaining Treatment (POLST) that are transferable between venues. A retrospective chart review of an elderly care program showed that POLST resulted in a high rate of concordance between POLST documents and the care patients received (91% of DNR orders followed). A survey evaluation of emergency medical technicians suggested that care in the field was altered according to wishes specified in POLST documents and that they were pleased with the program. The POLST mechanism has been translated into more than a dozen venues across the United States. Although other ways of improving continuity of end-of-life treatment have been suggested, such as directly communicating advance directives to a receiving facility, converting patient-centered treatment goals into actionable medical orders is also an effective approach.

Experts agree than continuity of advance directives and information collected during ACP is a minimal standard of quality. Oncologists should ensure that advance directives are relevant and available for use across the many venues in which a patient may receive care. Proven transport mechanisms that ensure these goals are met should be used when available (Table 1).

### CONCLUSION

Although information transfer and ACP in cancer care require individualization and the art of medicine guides many of our approaches for communicating with patients, we identified a number of clinical practices for which the literature and expert evaluation suggest that minimum standards of practice exist. We point out that many of these practices are not yet the norm in oncologic practice. These standards should be incorporated into care pathways and should become the expectation rather than the exception.

### AUTHORS’ DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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- [Author's Name] indicated a financial interest in the form of [nature of financial interest].
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Expert Testimony: None Other Remuneration: Arash NAaeim, Pfizer, Amgen Inc

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Final approval of manuscript: Anne Walling, Karl A. Lorenz, Sydney M. Dy, Arash NAaeim, Homayoon Sanati, Steven M. Asch, Neil S. Wenger

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AUTHOR CONTRIBUTIONS

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