RAND HEALTH

Appropriateness of Quality Indicators for Older Patients with Advanced Dementia and Poor Prognosis

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OBJECTIVES: To evaluate the applicability of process-of-care quality indicators (QIs) to vulnerable elders and to measure the effect of excluding indicators based on patients' preferences and for advanced dementia and poor prognosis.

DESIGN: The Assessing Care of Vulnerable Elders (ACOVE) project employed 203 QIs for care of 22 conditions (including six geriatric syndromes and 11 age-associated diseases) for community-based persons aged 65 and older at increased risk of functional decline or death. Relevant QIs were excluded for persons deciding against hospitalization or surgery. A 12-member clinical committee (CC) of geriatric experts rated whether each QI should be applied in scoring quality of care for persons with advanced dementia (AdvDem) or poor prognosis (PoorProg). Using content analysis, CC ratings were formulated into a model of QI exclusion. Quality scores with and without excluded QIs were compared.

SETTING: Enrollees in two senior managed care plans, one in the northeast United States and the other in the southwest.

PARTICIPANTS: CC members evaluated applicability of QIs. QIs were applied to 372 vulnerable elders in two senior managed care plans.

MEASUREMENTS: Frequency and type of QIs excluded and the effect of excluding QIs on quality of care scores.

RESULTS: Of the 203 QIs, a patient's preference against hospitalization or surgery excluded 10 and eight QIs, respectively. The CC voted to exclude 81.5 QIs (40%) for patients with AdvDem and 70 QIs (34%) for patients with PoorProg. Content analysis of the CC votes revealed that QIs aimed at care coordination, safety or prevention of decline, or short-term clinical improvement or prevention with nonburdensome interventions were usually voted for inclusion (90% and 98% included for AdvDem and PoorProg, respectively), but QIs directed at long-term benefit or requiring interventions of moderate to heavy burden were usually excluded (16% and 19% included, respectively). About half of QIs aimed at age-associated diseases were voted for exclusion, whereas fewer than one-quarter of QIs for geriatric syndromes were excluded. Thirty-nine patients (10%) in our field trial held preferences or had clinical conditions that would have excluded 68 QIs. This accounted for 5% of all QIs triggered by these 39 patients and 0.6% of QIs overall. The quality score without exclusion was 0.57 and with exclusion was 0.58 ($P = .89$).

CONCLUSION: Caution is required in applying QIs to vulnerable elders. QIs for geriatric syndromes are more likely to be applicable to these individuals than are QIs for age-associated diseases. The objectives of care, intervention burdens, and interval before anticipated benefit affect QI applicability. At least for patients with AdvDem and PoorProg, identification of applicable or inapplicable QIs is feasible. In a community-based sample of vulnerable elders, few QIs are excluded. **J Am Geriatr Soc 51:902–907, 2003.**

Key words: quality of care; vulnerable elders; geriatric syndromes

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An axiom of good medical practice is that management of patients' illnesses should be individualized. Even the most firmly established standards for prevention, diagnosis, and treatment cannot be applied to all patients. Un-

fortunately, this valued clinical principle complicates the assessment of the quality of health care. This is particularly true for patients with advanced illness or those with compromised quality of life.[1,2] Thus, an essential step in measuring quality of care is to determine whether the benefit from an intervention is so small for patients in the most debilitated condition that a quality indicator (QI) is inapplicable.

The Assessing Care of Vulnerable Elders (ACOVE) project developed a set of indicators for processes of care provided to vulnerable elders.[3] These indicators aimed to measure comprehensively the most important aspects of care provided to community-based persons aged 65 and older at four times the risk of death or functional decline over the subsequent 2 years.[4] Two hundred three indicators assessing care for 22 conditions were found to be applicable to measure the quality of care provided to vulnerable elders using the medical record and interview. Scoring of the indicators was designed to be responsive to specific care preferences expressed by the patient or a surrogate as recorded in the chart or by interview. The current study aimed to identify indicators that should not be applied in the setting of more-general preferences or for patients in severely debilitated condition.

Although QI systems are widely used to assess medical care, most measurement systems use an upper age limit to avoid patients who might not desire specified care processes or who might be too sick to benefit; others simply ignore the issue. This is an obstacle to developing quality indicators for older sick patients. There is no awareness of any established criterion or method to determine applicability of QIs to persons with debilitating illness. A conceptual basis was sought for setting rules for inclusion or exclusion of QIs for two major groups of patients: those with advanced dementia (AdvDem) and those with a poor prognosis (PoorProg) for survival. This report describes the method adopted to reach clinically relevant, internally consistent decisions for the application of QIs based on preferences and for patients with two serious conditions. This method was then applied to the data from vulnerable older people enrolled in the ACOVE field trial.

METHODS

The ACOVE measurement set comprised rules, termed QIs, for the provision of medical care to vulnerable elders in the community. Steps in the generation of the QIs have been detailed elsewhere.[5] QIs measure whether specific processes of care are provided to patients with specific clinical criteria. QIs are structured with an IF clause indicating eligibility of the patient for consideration of the QI and a THEN clause representing the required intervention. For each QI, content experts, who formulated the QIs, delineated the explicit link between the care process in the THEN statement and outcomes of care, and members of an expert panel and the clinical committee (CC), who voted on validity and feasibility of the QIs, considered them. The formal process resulted in approval of 236 QIs covering 22 conditions as targets for quality improvement,[6] of which 203 could be implemented in the ACOVE field trial. Six of the conditions were geriatric syndromes (dementia/delirium, terminal illness, falls/mobility disorders, malnutrition, pressure ulcers, and uri-
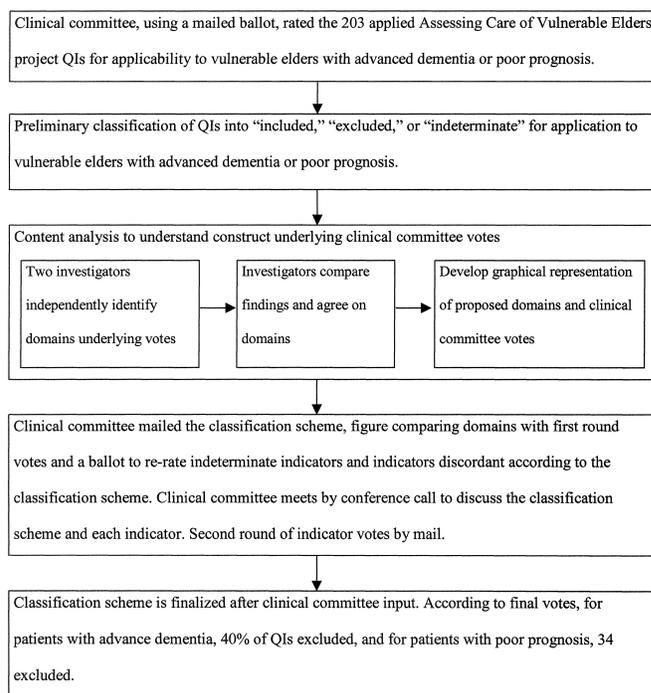

Figure 1. Method of exclusion of quality indicators (QIs) for older patients with advanced dementia and poor prognosis.

nary incontinence), 11 were age-associated diseases (depression, diabetes mellitus, hearing impairment, heart failure, hypertension, ischemic heart disease, osteoarthritis, osteoporosis, pneumonia, stroke, and vision impairment), and five fit into five cross-cutting processes of care (continuity of care, hospital care, medication use, pain management, and screening/prevention).

Based on clinical criteria, 10 of the QIs were excluded from application to patients who expressed a preference against hospitalization, and eight were excluded from patients who preferred not to receive surgery. For the task of delineating appropriate QIs for assessing care for patients with AdvDem or PoorProg, we adopted a formal analytic process involving the CC (Figure 1).

Specification of QIs for the Assessment of Care of Persons with AdvDem and PoorProg

Using the RAND-modified Delphi format, we presented all 203 implemented QIs to members of the CC by mail and asked each member to vote independently on whether to include or exclude each QI in the assessment of care for patients with AdvDem or PoorProg. Separate votes were cast for AdvDem and PoorProg. Eleven of the 12 members of the committee voted. Based on the bimodal distribution of the votes, a cutoff was established to include QIs with zero to four votes and to exclude those with six to 11 votes; the 5% of QIs receiving five votes were considered indeterminate on the basis of lack of agreement.

AdvDem was defined as a degree of dementia synonymous with Stages 6 or 7 of Reisberg's Global Deterioration Scale[7] (severe enough to interfere with basic activities of daily living and require continuous assistance). Mini-Mental State Examination scores would generally be below 11. AdvDem was diagnosed if the medical record de-

scribed dementia as advanced or severe or if any of the following characteristics was documented by the medical record or interview and could not be ascribed to another condition: no recent memory, severely impaired remote memory, minimal or no recognition of loved ones, bedridden, unable to ambulate, unable to eat or swallow, all activities of daily living lost, requiring continuous supervision, incontinent, or language garbled or mute. In the interview, a surrogate reporting that the patient had dementia or memory impairment that was described by a physician as severe or advanced identified AdvDem.

PoorProg was defined by requiring that the vulnerable elder have a lethal condition and an estimated life expectancy of 6 months or less. The evidence was a statement in the medical record of an estimated prognosis of 6 months or less or words and phrases such as "gravely ill," "terminally ill," "terminal," "near death," "moribund," or "has end-stage disease" (of a lethal illness such as heart failure or metastatic cancer). A patient enrolled in hospice care also met the definition of PoorProg.

A content analysis of the CC's initial votes was performed to elicit the themes underlying the decisions to exclude QIs from patients with AdvDem and PoorProg. Two investigators (DS, NW) independently identified the characteristics of the QIs receiving high or low numbers of votes for exclusion. The investigators subsequently compared their findings and arrived at a unified set of domains used to classify all QIs in the set. These domains were the burdensomeness (light, moderate, or heavy) and the goal (care continuity and coordination, patient safety and prevention of decline, short-term clinical or quality-of-life improvement, short-term prevention, medium- to long-term clinical improvement, or long-term prevention) of the care process. For example, the QI that requires a fall evaluation for a patient who sustained multiple falls or a fall with injury was classified as "light burden" and having the goal of "patient safety and prevention of decline." Alternatively, the QI that requires patients with severe knee osteoarthritis to undergo evaluation for total knee replacement was classified as "heavy burden" and "medium- to long-term clinical improvement." According to the classification scheme, the intersection of the goals and burdens of the care process categorized whether a QI would be included or excluded for assessment of care among patients with PoorProg and AdvDem. Low burden and short-term benefit QIs were expected to be included, with all others expected to be excluded. Thus, the fall evaluation QI was included and the knee arthroplasty QI was excluded for PoorProg and AdvDem patients. The classification scheme was subsequently presented to the CC to test concordance with their notions of how their decisions were made.

The relationship between the goals and burdens classification categories and the votes of the CC was presented graphically, highlighting CC decisions that did not match the expected pattern. The figure was mailed to the CC along with an accompanying ballot. CC members were asked to review the inclusion/exclusion decisions of all 203 QIs. They were asked to vote again on QIs that had received five votes on the initial ballot (indeterminate votes) and QIs for which the vote did not match the classification scheme (a total of 36 QIs, or 9% of all the QIs). Instructions to the CC emphasized that marking a QI for

exclusion did not mean that it would necessarily be wrong for the primary care physician to have carried out the intervention called for in the THEN clause. Rather, it meant only that the primary care physician should not be penalized for failing to carry out the intervention if the benefit from it might be so small or the risk so great that the QI would be inapplicable.

A meeting of the CC was held by conference call attended by nine members. First the conceptual model derived from the votes was again presented, and critique was requested. CC members broadly agreed that the model captured the concepts invoked in making the exclusion decisions. Twenty-three QIs were discussed regarding applicability to patients with AdvDem and 13 for PoorProg. After discussion, CC members re-voted. We defined zero to four votes as calling for inclusion of the QI and five to nine for exclusion. The distribution was bimodal. For AdvDem, nine QIs received one to three votes for exclusion, none received four, two received five, and 13 received six to nine votes (adds to 24 because the CC split one QI into two parts). For PoorProg, six QIs received one to three votes for exclusion and seven QIs had seven or more votes.

Application of QI Exclusion in the ACOVE Sample

The feasibility was tested, and the effect of applying the exclusion/inclusion system in the ACOVE field trial was evaluated. Enrollees (n = 2,567) in two senior managed care plans, one in the northeast United States and the other in the southwest, were identified by randomly selecting patients who met the criteria of at least 1 year of continuous enrollment in the plan, no out-of-plan care, and no active treatment for malignancy during the past year. Eligible subjects were contacted by telephone to assess ability to speak English and to administer a 13-item survey to identify vulnerable individuals at increased risk of functional decline or death.[4] Two hundred eighty-nine refused to complete the interview. If patients were incapable or preferred, proxies were interviewed. Of the 2,278 interviews conducted successfully, there were 475 vulnerable subjects. Four hundred twenty (88%) agreed to participate and to release medical records. Medical records were obtained for 400 patients; 28 received no care (or only a flu shot) during the study period, so the number of patients with charts reviewed was 372 (78%). Of these 372 patients, 245 (66%) patients or proxies were interviewed. The RAND institutional review board approved the study protocol.

Information to trigger and score the QIs was derived from a comprehensive compilation of medical records covering a 13-month period. All outpatient and inpatient charts were reviewed, including mental health, nursing home, and home care records. Information on care processes was also elicited by a quality-of-care interview conducted with the patient or proxy. Information about patients' preferences concerning hospitalization and surgery was obtained from documentation in the medical record or information elicited during the quality-of-care interview. These interview items, embedded in a preferences for care module, asked patients, "Now, I would like to ask you about the kind of medical care that you want if you get sick. Some people would want every medical treatment that might

help them. Others only want treatments that won't bother them too much. We ask these questions of every person that we interview. You don't need to answer them if you don't want to. If you were sick and needed hospital care, would you agree to go to the hospital?" Patients preferring to avoid the hospital were asked, "Would you stay away from the hospital, even if it meant that you might die sooner." Analogous items were asked concerning surgery.

Quality-of-care assessment was performed by identifying QIs triggered by study subjects and then evaluating whether the specified care process was carried out. If the care process occurred, then the QI was given a score of one; otherwise a score of zero was assigned. For QIs that could be triggered multiple times, a score between zero and one was possible. If the chart documented that a patient refused the care process, the QI was credited as carried out, because it was assumed that the clinician offered the care process and the patient chose otherwise. Quality was computed for each patient as the number of QIs passed divided by the number of QIs triggered. This computation was performed first without considering QI exclusions and then after QI exclusion. The frequency of excluded QIs was evaluated, and quality scores before and after exclusion were compared using a paired Wilcoxon test.

RESULTS

The CC assessment resulted in 81.5 (40%) QIs excluded for patients with AdvDem and 70 (34%) QIs excluded for patients with PoorProg. In addition, 10 QIs were excluded from application to patients who expressed a preference against hospitalization and eight for patients who preferred not to undergo surgery. However, there was extensive overlap among the four causes for exclusion, with the result that only 82.5 of 203 QIs (41%) were excluded from application to one or more of these four subgroups of patients.

The content analysis of the preliminary votes of the CC yielded a categorization of QIs with two core domains (the goal of the intervention and the burden of the intervention). Six goals of intervention were identified: continuity and coordination of care, patient safety and prevention of functional deterioration, short-term clinical or quality-of-life improvement, medium- to long-term clinical improvement, short-term prevention, and long-term prevention. Short-term was defined as days to weeks. Burdens were categorized as light, moderate, or heavy. Light-burden interventions included elements of the history or examination (excluding genital examination), prescribing oral medications, and simple procedures such as drawing blood or performing an electrocardiogram. In categorizing care processes as moderate or heavy burden, consideration was given to pain, danger, need for physical exertion, and difficulty of transport to additional clinician visits. For example, the repeated blood tests required for monitoring the international normalized ratio (INR) in warfarin therapy and a course of physical therapy were considered to be moderate burdens. Heavy-burden interventions included surgeries and invasive procedures.

Most light-burden QIs aimed at continuity and coordination of care, safety of the patient and prevention of functional deterioration, and short-term clinical improvement and prevention were included for quality assessment, whereas most processes of moderate or heavy burden and those focused on medium- or long-term clinical improvement and prevention were not. For patients with Poor-Prog, 117 of 120 QIs (98%) aimed at continuity, safety, and short-term improvement and prevention were voted for inclusion. For patients with AdvDem, 108.5 of 120 (90%) were included. (One QI, focusing on dementia evaluation, was split in two, with half excluded.) Nine of the excluded QIs in the light burden category, including all those excluded from the continuity and safety groups, were omitted due to impracticality rather than because the care process was not merited. For example, the CC judged that screening for suicidality was not possible for a patient with AdvDem diagnosed with depression. In the case of patients with PoorProg, only 16 of 83 (19%) QIs aimed at long-term clinical improvement or prevention or with moderate or heavy burden were voted for inclusion. In patients with AdvDem, only 13 of 83 (16%) such QIs were voted for inclusion. A description of each of the QIs voted for exclusion is available upon request to the authors. The entire set of 236 can be found in our previous ACOVE publication.[6]

There was considerable variation among the 22 conditions for quality improvement in the number of QIs voted for exclusion (Table 1). When these conditions were grouped into the 11 age-associated diseases or conditions, the six geriatric syndromes and the five crosscutting processes of care, striking differences emerged. For patients with AdvDem, 63 of the 113 (56%) QIs for age-associated diseases were voted for exclusion, whereas only 11.5 of 51 (23%) QIs relevant to the geriatric syndromes were so voted. For patients with PoorProg, 57 QIs for age-associated diseases were excluded (50%), whereas only six QIs for geriatric syndromes were excluded (12%). Among the crosscutting processes of care, no QI for continuity and coordination of care, hospital care, pain management, or medication use was voted for exclusion for AdvDem or PoorProg. However, seven of nine QIs for screening and prevention were voted for exclusion in the presence of AdvDem or PoorProg (Table 1).

Application of QI Exclusions to a Community Sample

Of the 372 community-dwelling vulnerable elders in the ACOVE cohort, 39 (10%) had a reason for exclusion of one or more QIs. Thirty-five of these patients evidenced a preference not to receive surgery. Five of these were documented only in the chart, 29 were identified only at interview, and one was found from both sources. Of this group desiring no surgery, six also expressed a preference not to be hospitalized, and one was identified by the chart as having PoorProg. One patient had chart documentation opposing hospitalization. Medical records noted that two patients had AdvDem (one with chart documentation against surgery), and two had PoorProg (one of whom expressed a preference against surgery and hospitalization at interview).

These 39 patients triggered 1,366 QIs, of which 68 (5%) were excluded. These excluded QIs accounted for 0.6% of all QIs triggered by the 372 ACOVE patients whose medical records were evaluated. For these 39 patients, the quality score without exclusion was 0.57 and with exclusion was 0.58 ($P = .89$).

Table 1. Exclusion of Quality Indicators for Medical and Geriatric Conditions and for Processes of Care

Condition	Total Number of QIs	Advance Dementia		Poor Prognosis	
		Include	Exclude	Include	Exclude
Medical conditions, n					
Depression	13	8	5	13	0
Diabetes mellitus	10	0	10	0	10
Hearing impairment	4	0	4	1	3
Heart failure	13	10	3	10	3
Hypertension	8	3	5	3	5
Ischemic heart disease	13	3	10	3	10
Osteoarthritis	11	6	5	6	5
Osteoporosis	10	0	10	0	10
Pneumonia	7	5	2	4	3
Stroke and arterial fibrillation	11	7	4	7	4
Visual impairment	13	8	5	9	4
Total, n (%)	113	50 (44)	63 (56)	56 (50)	57 (50)
Geriatric syndromes, n					
Dementia/delirium	11	6.5	4.5	9	2
End-of-life care	8	8	0	8	0
Falls	6	3	3	4	2
Malnutrition	7	5	2	5	2
Pressure ulcers	9	9	0	9	0
Urinary incontinence	10	8	2	10	0
Total, n (%)	51	39.5 (77)	11.5 (23)	45 (88)	6 (12)
Processes of care, n					
Continuity of care	8	8	0	8	0
Hospital care	4	4	0	4	0
Medication use	11	11	0	11	0
Pain management	7	7	0	7	0
Screening/prevention	9	2	7	2	7
Total, n (%)	39	32 (82)	7 (18)	32 (82)	7 (18)
Grand total, n (%)	203	121.5 (60)	81.5 (40)	131 (65)	69 (35)

DISCUSSION

A two-stage decision process using the RAND modified Delphi format defined the applicability of quality-of-care process measures for patients with very serious illness. This empirical classification system considered the goal and burden of the mandated intervention. This system is similar in some respects to the taxonomy for goal-setting in the face of chronic disease proposed in another study,[8] which was based on qualitative analysis of interviews that defined the principal goals of care as safety, independence, day-to-day functioning, social and family relationships, diagnosis, and management. This study[8] also classified goals as short-, intermediate-, and long-term, and factored in the challenge to the patient imposed by the goal. Our classification of care directed at safety, prevention of functional decline, and clinical improvement is congruent with the goals of care in this previous study,[8] but in the present study, the QIs did not address social and family relationships, and the other study did not address continuity and coordination of care.[8] Both classification systems included the concepts of time to expected benefit and the burden imposed by the intervention.

The guiding principle for exclusion of a QI in the present study was that the clinical situation (AdvDem or PoorProg) changed a QI from mandatory to a "judgment call" by the physician. Furthermore, because the viewpoint of patients and surrogates may differ from those of healthcare providers, there is a consensus that the decision should not be the responsibility of the physician alone; all involved parties should be consulted,[8,9] although it must be noted that substituted judgment by surrogates is often inaccurate.[10]

In the case of dementia, one study identified some of the reasons why certain treatments should be applied with great caution.[2] The report specified decreased decision-making capacity, delay in reporting or failure to report adverse effects, and problems with treatment adherence, as well as the basic question of what is an acceptable burden or risk of treatment in patients with limited prognosis for cognition or survival. Several other studies have outlined general principles of care of patients in the successive stages of dementia, [11–13] but these guidelines appear to be overlooked in the routine of inpatient care.[14] Studies of patients with poor prognosis for survival have unearthed a wide range of patient and surrogate preferences, although the dominant ones are comfort care and good communication.[15,16]

In the present study, the pattern of QI exclusion was similar for patients with PoorProg or AdvDem. Somewhat

more QIs were excluded for patients with AdvDem because inability of the patient to participate in decision-making rendered some QIs less applicable.

Far fewer QIs for geriatric syndromes were rated for exclusion than was the case for age-associated diseases. Diagnosis and treatment of geriatric syndromes may be more likely to improve quality of life (e.g., treatment of incontinence) and enhance patient safety (e.g., prevention of falls), whereas many QIs for diagnosis and treatment of age-associated diseases were perceived as aimed at prolonged survival. The CC decisions demonstrate that prolonged survival is less important than comfort and safety for patients with PoorProg or AdvDem.

The typology used here could be applied to other systems for measuring quality of care, particularly care for older persons. For example, systems depending on outcome measures could be improved by rating outcomes on their importance for the average member of the population under examination.[17,18] Mortality might be rated quite low for patients with advanced dementia or widespread metastatic carcinoma, but the incidence of falls or freedom from pain might be rated as important measures of quality of care.

The exclusion system presented here resulted in identification of 40% of QIs from the set of 203 as potentially excludable for subgroups of patients. When applied to a community-based cohort of individuals aged 65 and older who were at increased risk of death and functional decline, but in most cases not frail, only a minority of patients qualified for exclusion of any QI. This indicates that, at least for the four conditions or preferences identified as excluding QIs in this study, a broad-based system of quality measurement (such as that applied here, including more than 200 QIs) provides robust quality measurements that are not substantially affected by exclusions. However, the small number of subjects for whom QIs were excluded limits the power of the calculation that the quality score was unaffected by whether QIs were excluded or not. It is likely that the use of exclusions would be more important in studying populations of frail elders, such as nursing home patients or demented patients undergoing home care.

The techniques described in this paper may be even more important for quality measurement in frail older persons, a more-dependent population than the vulnerable group studied. Measures of quality are sparse for such groups, in part because of concerns that quality measures will not apply because the benefit from interventions is so small for patients in the most debilitated condition that QIs are inapplicable. The authors demonstrated that this postulate can be tested. Quality measurement systems can be applied to debilitated patient samples with a focus on the goals of care important to the targeted group.

Decision-making regarding application of QIs proved to be feasible, but another committee of geriatricians and other clinicians might make different decisions, so interrater reliability studies are needed. Another limitation of the present study is that the CC never met face to face to discuss whether QIs should be included or excluded. However, the committee members already were familiar with each other and the rating process as a result of attending prior meetings. The committee was heavily weighted with physicians (10 physicians, one nurse, and one social worker). One study reported that families, case managers, and physicians rated goals of care differently,[8] and another study found differences between patients, physicians, and nurses in ratings of health-related quality of life of nursing home residents.[9] It is likely that decisions on the applicability of QIs would also differ between groups of observers, so it would be useful to repeat the present study, with family members, nurses, or social workers making up the majority of the decision-making committee.

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