8. Improving Health Care and Palliative Care for Advanced and Serious Illness

Closing the Quality Gap: Revisiting the State of the Science

Executive Summary

Background

Although extensive evidence supports the effectiveness of clinical interventions for improving palliative care for patients with advanced and serious illness, many studies have found that these interventions are often not used sufficiently in practice.\(^1,2\) As part of a larger review of interventions aimed at reducing the quality gap (the difference between health care processes or outcomes observed in practice and evidence-based practices potentially obtainable on the basis of current professional knowledge), we conducted a review focusing on interventions to improve care and outcomes in patients with advanced and serious illness. We defined the included population as seriously ill patients and those with advanced disease (such as people living with advanced cancer or intensive care unit patients at high risk of dying) who are unlikely to be cured, recover, or stabilize.\(^3,4\) We classified interventions to improve care for this population by the framework shown in Figure A.\(^5\) The framework shows the literature in palliative care as a grid, with different populations, domains of care, targets of quality improvement, settings (and integrated care), conditions, and categories of relevant interventions. The targets show the areas where an intervention might focus—such as an intervention specifically targeting pain management in patients with advanced disease. Areas that were the focus of this review are underlined in the figure.

Evidence-based Practice Program

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

The full report and this summary are available at www.effectivehealthcare.ahrq.gov/reports/final.cfm.
Objectives and Key Questions

The objective of this report was to evaluate the effectiveness of health care and palliative care interventions on patient-centered outcomes relevant to palliative care, including quality improvement interventions. For the purpose of this review, we focused on targets related to palliative care, including pain; communication and decisionmaking; continuity, coordination, and transitions of care; and patient and family distress (defined as an unpleasant emotional experience that can be psychological, social, and/or spiritual). We also focused specifically on interventions within hospice care and in the nursing home setting. We analyzed studies to address how different types of quality improvement interventions can improve these targets of care in terms of populations, settings, and outcomes.

The Key Questions for the report follow.

Key Question 1: What is the effectiveness of health care and palliative care interventions for improving the quality of palliative care?

a. Specific targets: What is the effectiveness in terms of processes and outcomes for pain; communication and decisionmaking; continuity, coordination, and transitions of care; and patient and family distress in palliative care populations?

b. Specific settings: What is the effectiveness of interventions for any target of palliative care within hospice programs or nursing homes?

Figure A. Analytic framework for interventions for advanced and serious illness systematic review

Note: Areas that were the focus of this review are underlined.
Key Question 2: What is the evidence for different quality improvement models for improving palliative care?

a. What is the evidence for different types of quality improvement interventions?

b. What is the evidence for different models in palliative care: integrative compared with consultative?

We evaluated each target for whether Key Question 2a or 2b was more applicable, and only one of these questions was analyzed for each target. (They were mutually exclusive.)

“Health care and palliative care interventions” apply to interventions to improve care, including quality improvement interventions.

The intent of the Key Questions was to describe the evidence in each area (e.g., target, quality improvement type, setting), not to compare the different areas with each other.

“Targets” relate to the targets of the intervention, such as pain; communication and decisionmaking; continuity, coordination, and transitions; and patient and family distress, and not to outcomes. (see column 3 in Figure A).

“Integrative” refers to interventions that embed palliative care principles and interventions into daily practice, and “consultative” refers to interventions that increase the use and effectiveness of palliative care consultants or other nonintegrative interventions (see column 5 in Figure A).

Methods

Inclusion and Exclusion Criteria

We included studies on seriously ill patients and those with advanced disease who met the population definition given below, including studies on pediatric and geriatric populations. We also included studies with outcomes related to the families/caregivers of these patients. Patients with all conditions (e.g., cancer, heart failure, end-stage lung disease, dementia, and frailty) were included.

Since there are high-quality studies in this field, we excluded all retrospective and uncontrolled studies of interventions. We excluded individual studies published before 2000 because the nature of both quality improvement and palliative care practice has changed substantially since that time. Palliative care has grown markedly as a specialty and service since 2000, and the populations served by hospice care were also markedly different before 2000. In addition, the pre-2000 data have been thoroughly addressed in a previous Evidence-based Practice Center report and an extensive National Institute for Clinical Excellence (United Kingdom) report.

We included any timing of followup, including interviews after the patient’s death with families/caregivers. We addressed all settings, both inpatient and outpatient, as well as interventions in inpatient or outpatient hospice or palliative care programs.

The detailed PICOTS (populations, interventions, comparators, outcomes, timing, and setting) eligibility criteria used for inclusion/exclusion of articles for Key Questions 1 and 2 in this topic area follow.

Population(s)

We defined the relevant population as “seriously ill patients and those with advanced disease (such as people living with advanced cancer or intensive care unit patients at high risk of dying), who are unlikely to be cured, recover, or stabilize” (adapted from the National Consensus Project).

Interventions

We included studies evaluating health care and palliative care interventions, including quality improvement interventions, such as patient education and self-management, and provider audit and feedback.

Comparators

We included all comparators. For most studies, this was usual health care, but some studies tested interventions that were added to usual hospice or palliative care.

Outcome Measures for Each Key Question

For both Key Questions, we included all relevant patient or family/caregiver-centered outcomes, including:

- Patient and family satisfaction/perceptions of palliative care
- Patient symptoms, needs, distress, and quality of life
- Health care utilization, such as hospital admissions or do-not-resuscitate orders (but not costs)
- Quality-of-care measures, such as timeliness of response to pain and other symptoms
- Family/caregiver psychosocial symptoms, support, needs, quality of life, and grief/bereavement

We excluded studies that did not report measurements of any of these outcomes or that only had outcomes not related directly to the target populations (e.g., staff knowledge or perceptions of care).

Timing

We included any timing of followup, including interviews after the patient’s death with families/caregivers.
Settings
We addressed all settings, both inpatient and outpatient, with a specific focus on the nursing home setting (primary) and hospice program setting (specialty), as underlined in the analytic framework (see column 4 in Figure A).

Input From Experts
We developed questions in consultation with a variety of technical experts from areas of research, clinical care, and policy.

Data Sources and Selection
We searched PubMed®, CINAHL, PsycINFO, Cochrane, and DARE from 2000 through 2011. We identified additional studies from reference lists of eligible articles and relevant reviews, as well as from technical experts. We limited our review to prospective intervention studies that included a control group.

Data Extraction and Quality Assessment
Each abstract was independently screened by two reviewers. These reviewers included a trained article screener and a content expert. Abstracts were promoted to be screened using the full-text article if both reviewers agreed that the abstract could apply to one or more of the Key Questions. An abstract could be excluded for different reasons by the two reviewers. Disagreements about the eligibility of an abstract were resolved by discussion between the two reviewers or by adjudication of a third reviewer.

Full-text articles underwent another independent review by paired investigators. If articles were deemed to have applicable information, they were included for data abstraction. Articles were promoted to data abstraction if both reviewers agreed. An article could be excluded for different reasons by the two reviewers. Disagreements about the eligibility of an article were resolved by discussion between the two reviewers or by adjudication of a third reviewer.

All screening was completed using the DistillerSR Web-based systematic review software (Evidence Partners, Ontario, Canada).

No forms were used for data abstraction in this systematic review. Due to the nature of the data (narrative), we used a consecutive two-reviewer process to abstract data from the included articles. In this process, a research assistant abstracted data directly to tables, and these data were checked by a senior investigator. Periodically, senior investigators cross-checked the work of the other senior investigators to ensure that abstractions were done appropriately. Reviewers were not masked to the articles’ authors, institutions, or journal. Disagreements that could not be resolved between the reviewers were resolved through consensus adjudication at team meetings.

We used a tool implemented successfully in past Evidence-based Practice Center projects, including the Cochrane Collaboration Tool for Assessing Risk of Bias from the Cochrane Handbook for Systematic Reviews of Interventions for assessing randomized controlled trials. Data abstraction forms were not developed for this phase of the review, and elements of the data abstraction can be found in the evidence tables.

We assessed the risk of bias and appropriateness of all studies that met our eligibility criteria, following the guidance contained in chapter 6 of the Agency for Healthcare Research and Quality’s Methods Guide for Effectiveness and Comparative Effectiveness Reviews. We used a limited number of the key criteria that are most appropriate for each study design and that are most important for determining the validity of the studies. After the pool of included articles in this review was determined, the core team of investigators determined that the Cochrane Collaboration tool was the tool most appropriate for all risk-of-bias assessments. Although we considered assessing risk of bias separately for nonrandomized studies, we were unable to identify any validated tools that worked well in this literature and could be compared with risk-of-bias tools designed for randomized trials. We did not factor in the quality score for blinding of the intervention; we did this because blinding of patients and personnel was generally not feasible in these interventions, although blinding of outcomes assessors would have been possible. A low risk of bias was assessed if six or more of the items were scored as a “yes.” A medium risk of bias was assessed if four or five of the items were scored as a “yes” or “unclear.” A high risk of bias was assessed if zero to three items were scored as a “yes.”

Data Synthesis
We adapted previous frameworks to categorize included studies by target and setting of the intervention, including a category for interventions that focused on multiple targets or targets other than the primary ones for this review, and evaluated each target category for applicability to each Key Question. Each target category was evaluated for applicability to either Key Question 2a (types of quality interventions) or Key Question 2b (integrative compared with consultative model) and evaluated only for that part of Key Question 2. To determine whether results could be quantitatively synthesized, we evaluated the diversity of studies, measurement tools, and outcome reporting. Because effect sizes were often not reported, most studies were small (<200 patients), interventions and outcomes...
were diverse, and there was concern for selective outcome reporting, we judged that quantitative synthesis was not appropriate due to clinical and methodological diversity. Therefore, to be consistent with most previous systematic reviews in this literature, for each category, we calculated the percentage of studies with a statistically significant improvement in outcomes with the intervention compared to control. We also checked that all other studies did not report significant results in the opposite direction.

**Grading**

We assessed the strength of the best available evidence, including the risk of bias in relevant studies, as well as aspects of consistency, directness, and precision where applicable. Based on these aspects, evidence for each outcome was graded as insufficient, low, moderate, or high.

**Results**

Results are summarized in Table A by target and outcome, and in the text below by Key Questions addressed for each target from Figure A. We included 90 studies described in 96 articles in the review (Figure B). We described the information abstracted in a systematic manner but did not conduct any meta-analyses. The interventions, outcomes, and outcome reporting were too diverse to allow for any synthesis.

**Interventions Targeting Continuity, Coordination of Care, and Transitions**

**Key Question 1a: Evidence About Target**

We found 23 studies described in 26 articles focusing on the targets of continuity, coordination of care, and/or transitions in care, including interventions such as palliative care consultation, case management, and hospice screening and referral. Twelve studies were randomized controlled trials (RCTs). The studies addressed a wide variety of populations, settings, and outcomes, with most studies evaluating multiple types of outcomes.

Of the nine studies that evaluated patient quality of life, only three (33 percent) showed a statistically significant improvement with the intervention compared with the control group. Of the six trials that evaluated patient satisfaction, four (67 percent) showed a statistically significant improvement with the intervention. Three of the five studies (60 percent) that evaluated family satisfaction showed a significant improvement. None of the eight studies that measured the effect on overall symptoms demonstrated a significant improvement with the intervention on this outcome. Only 5 of the 16 studies (31 percent) that evaluated health care utilization found a statistically significant improvement with the intervention on this outcome. Interventions and outcomes were too diverse for meta-analysis.

Strength of evidence was low for improvement in patient quality of life, symptoms, and health care utilization, and moderate for improvement in patient and family satisfaction.

**Key Question 1b: Evidence About Settings**

For hospice care, one RCT that examined systematic feedback from standardized assessments and interdisciplinary team discussions showed a statistically significant improvement with the intervention on one outcome. For nursing homes, one of three studies on care pathways showed a statistically significant improvement with the intervention, as did one study on screening for hospice eligibility.
Figure B. Results of the literature search

General Search
PubMed: 3,641
PsycINFO: 193
CINAHL: 1,093
Cochrane: 1,061
DARE: 1,058

Cancer Management and Pain Search
PubMed: 5,159
PsycINFO: 1,245
CINAHL: 2,853
Cochrane: 784
DARE: 381

Nursing Home and Care Planning/Pain Search
PubMed: 693
PsycINFO: 149
CINAHL: 520
Cochrane: 173
DARE: 1714

Total Retrieved
20,517

Duplicates
7,503

Title/Abstracts
13,014

Abstracts Excluded
12,567

Abstract exclusion reasons:
- Not a study about quality improvement: 10,524
- Does not address a palliative care intervention population: 2,324
- Does not include patient- and family-centered outcomes in the results: 388
- Not an included study design: 5,221
- Other: 60

Articles Screened
447

Articles Excluded
351

Articles Included
86

Article exclusion reasons:
- Not a study about quality improvement: 171
- Does not address a palliative care intervention population: 203
- Does not include patient- and family-centered outcomes in the results: 42
- Not an included study design: 84
- Other: 6

\[\text{The sum of reasons for exclusion at abstract screening is greater than the total number of exclusions because each reviewer could select a different reason for exclusion.}\]

\[\text{The sum of reasons for exclusion at article screening is greater than the total number of exclusions because each reviewer could select a different reason for exclusion.}\]
### Table A. Summary of key data, by target, for all types of quality improvement interventions and settings

<table>
<thead>
<tr>
<th>Target</th>
<th>Outcome</th>
<th>Strength of Evidence(^{a}) That the Intervention Improved Outcomes Compared With the Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuity, Coordination of Care, and Transitions (KQ1a and KQ2a)</td>
<td>Patient quality of life</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Patient satisfaction</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Caregiver burden</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Caregiver satisfaction</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Overall symptoms</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Health care utilization</td>
<td>Low</td>
</tr>
<tr>
<td>Pain (KQ1a and KQ2a)</td>
<td>Pain</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td>Quality of life</td>
<td>Low</td>
</tr>
<tr>
<td>Distress (KQ1a and KQ2a)</td>
<td>Distress</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>Low</td>
</tr>
<tr>
<td>Communication and Decisionmaking (KQ1a and KQ2b)</td>
<td>Patient satisfaction</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Family satisfaction</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Health care utilization</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Quality of life</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Symptom control</td>
<td>Low</td>
</tr>
<tr>
<td>Multiple and Other Targets (KQ2a)</td>
<td>Quality of life</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Quality of care</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Patient symptoms</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Psychosocial support</td>
<td>Low</td>
</tr>
</tbody>
</table>

\(^{a}\)Strength of evidence is based mainly on the strength of the study designs (with randomized trials considered the strongest design) and on consistency based on the percentage of studies with a statistically significant improvement in the outcome, while checking that no studies had a significant worsening of the outcome. This approach was necessary because of inconsistent reporting of outcomes across studies and frequent lack of reporting of effect size or confidence intervals.

Note: KQ = Key Question. KQ2a or KQ2b was analyzed for each target as more appropriate; they were mutually exclusive. Table does not address KQ1b; some targets did not have any hospice or nursing home studies, and none had more than a few—insufficient for strength of evidence by target. There were insufficient numbers of studies to compare different quality improvement types or quality improvement models within any of the targets.

**Key Question 2a: Evidence About Types of Quality Improvement**

For the outcomes of quality of life and satisfaction, studies using patient-centered quality improvement types, such as patient/family/caregiver education and promotion of self-management, showed a significant improvement in satisfaction and quality of life in six of nine studies. Of six studies that included provider-centered quality improvement interventions (provider reminder systems, facilitated relay of clinical data to providers, or provider education) but did not include patient-centered quality improvement interventions, none demonstrated effectiveness on quality of life or satisfaction. For the outcome of health care utilization, such as admissions or length of stay, only 5 of the 16 studies (31 percent) reported a statistically significant improvement with the intervention compared to the control group.

**Key Question 2b: Evidence About Integrative and Consultative Models**

This Key Question was not analyzed for this target.

**Interventions Targeting Pain**

**Key Question 1a: Evidence About Target**

We found 21 studies addressing the target of pain in patients with advanced and serious illness; 19 were in cancer populations. Sixteen studies were in the ambulatory setting, and 18 were RCTs. Fourteen studies used the Brief Pain Inventory as the pain measurement tool.
Ten of the studies (48 percent) found that the interventions had a statistically significant effect on improving pain scores. Similar findings were noted when including only larger studies (100-200 patients); 5 of these 11 studies (45 percent) had significant findings. The interventions and outcome measurement and reporting were too diverse, and reporting of effect sizes was too inconsistent, for quantitative synthesis, and there was concern about selective outcome reporting. Eight of the studies also measured quality of life as an outcome; only one of those studies found any effect of the intervention on quality of life, and this study found improvement on only a single subscale. Strength of evidence was moderate for improvement in pain and low for improvement in quality of life.

Key Question 1b: Evidence About Settings
Two RCTs targeted pain in nursing homes using pain screening interventions for end-stage dementia. Both found a statistically significant improvement with the intervention.

Key Question 2a: Evidence About Types of Quality Improvement
Three studies used provider-level interventions only, and 18 employed patient and/or family caregiver education and self-management. Half of the studies employing patient and/or family caregiver education and self-management used print or video material to enhance the intervention. Four of the six studies that used an educational video followed by printed materials to enhance the educational intervention showed statistically significant improvement in pain scores, compared with one of the three studies that used either print material alone or video material alone.

Key Question 2b: Evidence About Integrative and Consultative Models
This Key Question was not analyzed for this target.

Interventions Targeting Communication and Decisionmaking
Key Question 1a: Evidence About Target
We found 20 studies of interventions targeting communication and decisionmaking with patients with advanced and serious illness. Nine were RCTs, 13 were conducted in an intensive care unit, and most were in mixed-illness populations. Interventions included family meetings with the usual health care team (11 studies), interdisciplinary palliative care teams (4 studies), ethics consultations (2 studies), and physician-patient communication (2 studies). Only one of eight studies that evaluated patient satisfaction showed a statistically significant improvement with the intervention on this outcome, and one of three studies that evaluated family satisfaction showed a significant impact. On the other hand, of 15 studies that evaluated health care utilization as an outcome, 11 (73 percent) showed a statistically significant improvement with the intervention. Interventions and outcomes were too diverse for meta-analysis. Strength of evidence was low for improvement in satisfaction and moderate for improvement in health care utilization.

Key Question 1b: Evidence About Settings
No studies addressed hospice. One study, measuring end-of-life outcomes in nursing homes, found that educating providers, patients, and families about advance directives improved health care utilization, but there was no impact on satisfaction.

Key Question 2a: Evidence About Types of Quality Improvement
This Key Question was not analyzed for this target.
Key Question 2b: Evidence About Integrative and Consultative Models

Eight interventions were integrative, and four of the eight (50 percent) showed a statistically significant improvement with the intervention. Eight interventions were consultative, and six of the eight (75 percent) found a statistically significant improvement with the intervention. Only four studies combined integrative and consultative models.

Interventions Targeting Multiple and Other Targets

Key Question 1a: Evidence About Target

This Key Question was not analyzed for multiple and other targets.

Key Question 1b: Evidence About Settings

For the hospice setting, one study on training caregivers in symptom management techniques found a statistically significant improvement with the intervention. For the nursing home setting, one study of a provider education intervention showed a statistically significant improvement with the intervention, as did one study including multiple quality improvement types.

Key Question 2a: Evidence About Types of Quality Improvement

For facilitated relay of clinical data to providers, we found six publications on five studies. All were RCTs in cancer patients. The interventions involved health-related quality of life surveys with feedback to physicians. Only one of the five studies demonstrated that the intervention had a significant effect on quality of life or satisfaction. Of two studies of audit and feedback, a multicenter study found significant improvements, but a single-center study found no impact on measures of quality of care. The one study focusing on provider education in nursing homes found the intervention had a statistically significant improvement on measures of quality of care.

For patient/caregiver education and self-management, we found six publications on five studies that addressed multiple targets and symptoms or quality of life. Four of the five studies found statistically significant improvement with the intervention. We found one study focusing on organizational change (a before-after study of a rapid-response clinic for palliative radiotherapy), which found a statistically significant improvement in the use of single-fraction treatment (guideline-recommended care) and a reduction in time to treatment. We did not identify any studies for provider reminder systems or for financial incentives, regulation, and policy.

We identified three studies that focused on multiple quality improvement types and multiple targets. One study was an RCT based on an initial non-RCT. This RCT (in intensive care units) found no significant impact on any outcomes. Another study in the nursing home setting found a statistically significant improvement for multiple outcomes.

Finally, we found two studies that did not fit any of the quality improvement types. Both evaluated new clinical services in palliative care. One found no significant impact of a palliative daycare intervention and the second, an RCT of hospital services provided in the home setting for palliative care, found a statistically significant improvement with the intervention on only one of multiple outcomes measured. Interventions and outcomes were too diverse for meta-analysis, and strength of evidence was low for improvement in outcomes.

Key Question 2b: Evidence About Integrative and Consultative Models

This Key Question was not analyzed for multiple and other targets.

Discussion

Brief Review of Main Findings

Among the types of interventions evaluated in this report, for the target of continuity, coordination, and transitions, we found moderate strength of evidence for improvement in satisfaction but low strength of evidence for improvement in quality of life and health care utilization. In contrast, we found moderate strength of evidence for the target of communication and decisionmaking for improvement in the outcome of health care utilization but not for improvement in satisfaction; three-quarters of the interventions that evaluated utilization (mostly in the intensive care unit setting) found a statistically significant impact on health care utilization outcomes. Moderate strength of evidence was found for patient-centered pain interventions for improvement in the outcome of pain, and strength of evidence was low for improvement in distress. For studies addressing multiple targets, only one of five studies of facilitated relay of clinical data to providers found a statistically significant improvement with the intervention. In reference to the question of integrative compared with consultative interventions, for the target of communication and decisionmaking, three-quarters of consultative interventions showed a statistically significant improvement with the intervention, compared to half of integrative interventions. Seven of the nine interventions to improve care in the nursing home setting showed an improvement in at least one outcome. Although the quality of studies overall was mixed, we noted the presence of
selected high- and medium-quality, well-designed studies for most of the target areas and Key Questions.

**Description of Clinical Context and Applicability of Evidence for Decisionmaking**

Several high- and medium-quality, well-designed, multicenter interventions to improve health care for patients with advanced and serious illness with consistent results across outcomes now exist. However, this report highlights the continued presence of variable findings, study quality deficiencies, ill-defined interventions, and insufficient use of appropriate measurement tools for the intervention and for patients with advanced and serious illness in much of the literature.

For policymakers, this report underscores the continuing strong need for research funding for well-designed studies to evaluate quality improvement and policy interventions, particularly in areas that are advancing rapidly in health care policy (e.g., feedback and financial and regulatory interventions) but have not been rigorously evaluated.

**Summary of Weaknesses or Gaps of the Evidence and Description of Limitations of the Review**

As with all systematic reviews, our results and conclusions depend on the quality of the published literature. Due to clinical and methodological diversity in outcomes, populations, interventions, and measurement tools; concerns about selective outcome reporting; and lack of reporting of effect sizes or confidence intervals in most studies, we judged that qualitative description of the literature was more appropriate than quantitative synthesis. The quality of many studies was moderate to low. Common quality issues included small sample sizes, often due to insufficient recruitment and high rates of attrition, and issues with outcome measures not designed for advanced or serious illness or not well coordinated with the purpose of the intervention. Descriptions of interventions were often limited, difficult to interpret, and challenging to categorize into the quality improvement types. Few studies reported information on disparities, context, or theory or logic models.

**Implications for Future Research**

We identified several key areas for future research. The field of palliative care has clearly advanced significantly since the 2004 evidence report on end-of-life care and outcomes. The quality of research in this field could be improved by recruitment and retention efforts to assure adequate sample size, better development and description of interventions, inclusion of theory and quality improvement techniques, consideration of context, matching and pilot testing of outcomes for interventions, standardization of outcome measures across interventions, and clearer and consistent reporting of outcomes. Development of measurement instruments specific to this population has advanced, but more development is needed for measuring certain domains and to better understand how to match outcome measures to interventions. We identified few studies in hospice populations and no studies focusing on reducing disparities in outcomes.

In both these areas, there is significant need, and there are significant challenges in developing and evaluating quality improvement interventions. Finally, the use of different quality improvement types was limited in studies focusing on populations with serious and advanced illness, particularly for the targets of pain and distress.

**Conclusions**

In conclusion, we found the most consistent evidence in a large number of studies, including several high- and medium-quality studies, for the effectiveness of interventions targeting continuity for improvement in the outcome of patient satisfaction, targeting pain using patient-centered interventions, and targeting communication and decisionmaking for impacting health care utilization outcomes in the intensive care unit setting. The evidence has multiple gaps, including studies in illnesses other than cancer for symptom management; in pediatric populations and hospice settings; and addressing diverse populations and disparities in care. More coordinated initiatives across multiple settings and providers, and following patient populations over longer periods of time, will be needed to better understand how best to improve care and outcomes for patients with advanced and serious illness.

**References**


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