

Appendix C: Guideline and Systematic Review Search Results

| | Year | Title | Summary |
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| AHRQ: Research Findings and Reports | 2017 | Assessment Tools for Palliative Care | We identified more than 150 assessment tools addressing most domains of palliative care, but few tools addressed the spiritual, structure and process, ethical and legal, or cultural domains, or the patient-reported experience subdomain. While some data on the psychometric properties of tools exist, the responsiveness of different tools to change has largely not been evaluated. Future research should focus on: (1) developing or testing tools in palliative care populations for domains with few or no tools, (2) evaluating responsiveness of tools for all domains, and (3) further studying the use of palliative care tools in clinical care and as quality indicators. |
| | 2016 | Home-Based Primary Care Interventions | The services included in the HBPC interventions varied widely, and no identifiable combination was related to more positive outcomes. We identified four studies that evaluated the addition of specific services. Combining palliative care and primary care home visits increased the likelihood of death at home (2 studies; low strength of evidence), while studies on adding caregiver support (1 study) or transitional care (1 study) to HBPC were rated as having insufficient evidence. |
| | 2014 | Decision Aids for Advance Care Planning | Numerous decision aids are widely available but not represented in the empirical literature. Of the 16 published studies testing decision aids as interventions for adult ACP, most were proprietary or not openly available to the public. Decision aids tend to be constructed for the general population or for disease-specific conditions for narrower decision choices. Designing decision aids that are responsive to diverse philosophical perspectives and flexible to change as people gain experience with their personal illness courses remains an important concern. Future directions for effort include further research, training of ACP facilitators, dissemination and access, and the potential opportunities that lie in social media or other technologies. |
| | 2012 | Closing the Quality Gap Series: Improving Health Care and Palliative Care for Advanced and Serious Illness | We found that evidence was strongest (moderate strength of evidence) for interventions for pain, and for the targets of communication and decision making and continuity for selected outcomes. While a few high- and medium-quality, well-designed health care and palliative care interventions have been conducted to improve outcomes for patients with advanced and serious illness, this report highlights the continued presence of variable findings, quality deficiencies, vaguely defined interventions, and variable outcome measurement tools and reporting in much of this intervention literature. The evidence has a number of gaps, including few studies in the hospice setting or pediatrics. |
| | 2010 | A Review of Quality of Care Evaluation for the Palliation of Dyspnea | Systematic reviews identified only 3 existing quality measurement sets that included quality measures for dyspnea care. The existing dyspnea quality measures reported by retrospective evaluations of care assess only 4 aspects: dyspnea assessment within 48 hours of hospital admission, use of objective scales to rate dyspnea severity, identification of management plans, and evidence of dyspnea reduction...The panel |

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| | | recommended that dyspnea assessment should include a measure of intensity and some inquiry into the associated bother or distress experienced by the patient. A simple question into the presence or absence of dyspnea would be unlikely to help guide therapy, as complete relief of dyspnea in advanced disease would not be anticipated. |
| | 2010 | A Framework for Assessing Quality Indicators for Cancer Care at the End-of-Life The framework describes five steps for developing and assessing a quality indicator for end-of-life care, defining the (1) population of focus; (2) broad quality domains; (3) specific target areas; (4) steps of the care process; and (5) evaluation criteria for quality indicators. The defined population includes seriously or terminally ill cancer patients, who are unlikely to recover or stabilize, and their families. Domains include the structure and processes of care; physical, psychiatric, psychosocial, spiritual, and cultural aspects of care; as well as the care of the imminently dying, ethical legal issues, and the delivery of care. Evaluation criteria include importance; scientific acceptability, including validity, evidence to improve outcomes, reliability, responsiveness, and variability; usability; and feasibility, including ready data sources. |
| | 2010 | Cancer Quality-ASSIST Supportive Oncology Quality Indicator Set: Feasibility, Reliability, and Validity Testing We successfully evaluated 78 indicators across the domains; results were similar in the two settings. We could not feasibly evaluate 3 indicators because of low prevalence; 22 indicators had significant interrater reliability issues, 9 had significant validity issues, and 3 had both reliability and validity issues, leaving a set of 41 indicators most promising for further testing and use in this population, with an overall kappa score of 0.85 for specified care. |
| Cochrane Collection | 2017 | Early palliative care for adults with advanced cancer This systematic review of a small number of trials indicates that early palliative care interventions may have more beneficial effects on quality of life and symptom intensity among patients with advanced cancer than among those given usual/standard cancer care alone. Although we found only small effect sizes, these may be clinically relevant at an advanced disease stage with limited prognosis, at which time further decline in quality of life is very common. At this point, effects on mortality and depression are uncertain. We have to interpret current results with caution owing to very low to low certainty of current evidence and between-study differences regarding participant populations, interventions, and methods. Additional research now under way will present a clearer picture of the effect and specific indication of early palliative care. Upcoming results from several ongoing studies (N = 20) and studies awaiting assessment (N = 10) may increase the certainty of study results and may lead to improved decision making. In perspective, early palliative care is a newly emerging field, and well-conducted studies are needed to explicitly describe the components of early palliative care and control treatments, after blinding of participants and outcome assessors, and to report on possible adverse events. |
| | 2017 | Psychosocial interventions for fatigue during We found little evidence around the benefits of psychosocial interventions provided to reduce fatigue in adult patients with incurable cancer receiving cancer treatment with palliative intent. Additional studies with |

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| | cancer treatment with palliative intent | larger samples are required to assess whether psychosocial interventions are beneficial for addressing fatigue in patients with incurable cancer. |
| 2016 | Palliative care interventions in advanced dementia | Very little high quality work has been completed exploring palliative care interventions in advanced dementia. There were only two included studies in this review, with variation in the interventions and in the settings that made it impossible to conduct a meta-analysis of data for any outcome. Thus, we conclude that there is insufficient evidence to assess the effect of palliative care interventions in advanced dementia. The fact that there are six ongoing studies at the time of this review indicates an increased interest in this area by researchers, which is welcome and needed. |
| 2015 | Training and supportive programs for palliative care volunteers in community settings | The use of palliative care volunteers is likely to continue, but there is an absence of evidence to show how best to train or support them whilst maintaining standards of care for palliative care patients and their families. |
| 2015 | Psychological therapies for sickle cell disease and pain | Evidence for the efficacy of psychological therapies in sickle cell disease is currently limited. This systematic review has clearly identified the need for well-designed, adequately-powered, multicentre randomised controlled trials assessing the effectiveness of specific interventions in sickle cell disease. |
| 2013 | Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers | The results provide clear and reliable evidence that home palliative care increases the chance of dying at home and reduces symptom burden in particular for patients with cancer, without impacting on caregiver grief. This justifies providing home palliative care for patients who wish to die at home. More work is needed to study cost-effectiveness especially for people with non-malignant conditions, assessing place of death and appropriate outcomes that are sensitive to change and valid in these populations, and to compare different models of home palliative care, in powered studies. |
| 2012 | Spiritual and religious interventions for well-being of adults in the terminal phase of disease | We found inconclusive evidence that interventions with spiritual or religious components for adults in the terminal phase of a disease may or may not enhance well-being. Such interventions are under-evaluated. All five studies identified were undertaken in the same country, and in the multi-disciplinary palliative care interventions it is unclear if all participants received support from a chaplain or a spiritual counsellor. Moreover, it is unclear in all the studies whether the participants in the comparative groups received spiritual or religious support, or both, as part of routine care or from elsewhere. The paucity of quality research indicates a need for more rigorous studies. |

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| 2011 | Interventions for improving palliative care for older people living in nursing care homes | <p>We found few studies, and all were in the USA. Although the results are potentially promising, high quality trials of palliative care service delivery interventions which assess outcomes for residents are needed, particularly outside the USA. These should focus on measuring standard outcomes, assessing cost-effectiveness, and reducing bias.</p> |
| 2011 | Non-invasive interventions for improving well-being and quality of life in patients with lung cancer | <p>Nurse follow-up programmes and interventions to manage breathlessness may produce beneficial effects. Counselling may help patients cope more effectively with emotional symptoms, but the evidence is not conclusive. Other psychotherapeutic, psychosocial and educational interventions can play some role in improving patients' quality of life. Exercise programmes and nutritional interventions have not shown relevant and lasting improvements of quality of life. Reflexology may have some beneficial effects in the short term.</p> |
| 2009 | Multidisciplinary care for adults with amyotrophic lateral sclerosis or motor neuron disease | <p>In the absence of randomised controlled trials or controlled clinical trials, the 'best' evidence to date is based on three 'low' and two 'very low quality' observational studies. These suggest 'very low quality evidence' for an advantage for mental health domains (only) of quality of life without increasing healthcare costs, and 'low level quality' evidence for reduced hospitalisation for MDC in low-intensity outpatient settings; and 'very low quality' evidence for improved disability in high-intensity settings. The evidence for survival is conflicting. These conclusions are tentative and the gap in current research should not be interpreted as proof that MDC is ineffective. Further research is needed into appropriate study designs; outcome measurement; caregiver needs; and the evaluation of optimal settings, type, intensity or frequency and cost-effectiveness of MDC in the MND population. Future research should focus on observational designs to assess care and outcomes in 'real-life' settings. The interface between neurology, rehabilitation and palliative care should be explored to provide long-term support for MND.</p> |
| <p><i>Health Technology Assessment Program</i></p> | <p>None</p> | |
| <p><i>Centers for Disease Control and Prevention</i></p> | <p>Nothing specific, 2016 Opioid Prescribing Guidelines for Chronic Pain</p> | |

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| <p><i>Institute for Clinical and Economic Review</i></p> | <p><u>2016</u></p> | <p>Palliative Care in the Outpatient Setting</p> | <p>Overall, the evidence describing outpatient palliative care’s benefit is stronger for QoL, resource utilization outcomes, patient satisfaction, and mood outcomes, with more limited evidence suggesting benefits on survival, symptom burden, psychosocial, and caregiver outcomes. These observations are consistent with the fact that outpatient palliative care programs are designed to increase patient social support, patient self-advocacy, and coordinated medical care; while palliative care is not focused on improved survival as an indicator of effectiveness, the survival benefit may be mediated by the other more directly influenced outcomes of interest (e.g., mood, QoL).</p> |
| <p><i>Veterans Administration Evidence-based Synthesis Program</i></p> | <p><u>2017</u></p> | <p>Integrated Outpatient Palliative Care in Oncology</p> | <p>With the increase in availability of clinical palliative care services, organizations have tested and implemented varying degrees and types of integration with oncology care. These can be evaluated using common instruments, like the Integrated Practice Assessment Tool based on the health care integration framework by Heath et al. Adapted from this framework, levels of integration across palliative care and oncology have recently been proposed in the Collaborative Care Continuum framework by Kaufmann et al. In addition to levels of integration, leaders have described various methods of integration of services, including co-rounding models for hospitalized patients, embedded or co-located outpatient clinical services, and standalone clinics or services. Further, organizations have had positive experiences with integrated services limited to particular disease or conditions, types of therapy (eg, investigational agents or novel immunotherapy drugs), or by embedding palliative care experts into non-patient-facing case discussions such as multidisciplinary oncology team meetings (“tumor boards”). In addition to other types of integration, much focus has been on the outpatient setting, which is where the majority of cancer care is delivered. For palliative care, the outpatient realm has been considered the “next frontier” of community-based palliative care services, and although growth is robust, many communities do not have access to non-hospital services.</p> |

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| <i>National Consensus Project for Quality Palliative Care National Coalition for Hospice and Palliative Care</i> | <u>2018</u> | Clinical Practice Guidelines for Quality Palliative Care, 4th edition | <p>The NCP Guidelines, 4th edition, are organized into 8 domains:</p> <p>Domain 1: Structure and Processes of Care The composition of an interdisciplinary team is outlined, including the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Domain 1 also defines the elements of the palliative care assessment and care plan, as well as systems and processes specific to palliative care.</p> <p>Domain 2: Physical Aspects of Care The palliative care assessment, care planning, and treatment of physical symptoms are described, emphasizing patient- and family-directed holistic care.</p> <p>Domain 3: Psychological and Psychiatric Aspects The domain focuses on the processes for systematically assessing and addressing the psychological and psychiatric aspects of care in the context of serious illness.</p> <p>Domain 4: Social Aspects of Care Domain 4 outlines the palliative care approach to assessing and addressing patient and family social support needs.</p> <p>Domain 5: Spiritual, Religious, and Existential Aspects of Care The spiritual, religious, and existential aspects of care are described, including the importance of screening for unmet needs.</p> <p>Domain 6: Cultural Aspects of Care The domain outlines the ways in which culture influences both palliative care delivery and the experience of that care by the patient and family, from the time of diagnosis through death and bereavement.</p> <p>Domain 7: Care of the Patient Nearing the End of Life This domain focuses on the symptoms and situations that are common in the final days and weeks of life.</p> <p>Domain 8: Ethical and Legal Aspects of Care Content includes advance care planning, surrogate decision-making, regulatory and legal considerations, and related palliative care issues, focusing on ethical imperatives and processes to support patient autonomy.</p> |
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