


ESTABLISHING A NATIONAL FRAMEWORK FOR GERIATRIC HOMECARE EXCELLENCE
PALLIATIVE CARE AND ADVANCED ILLNESS MANAGEMENT
ARTICLE DESCRIPTIONS

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<p>Bugge (2006) * Limited systematic review to determine factors that influence informal adult education for patients with progressive illness who need symptomatic and palliative care.</p> <p>Interventions included multifaceted education, adult education, and printed material (e.g., leaflets, pamphlets).</p>	<p>28 articles (a total of studies 31) representing a variety of methods (interviews, questionnaires) and 5 Cochrane reviews</p>	<p>Health-care or any ‘one-to-one’ instructor setting for adult education <i>outside</i> the formally established educational settings (classrooms/schools and universities)</p>	<p>Individual responses (e.g., surveys, questionnaires) regarding outcomes of an educational process between adults</p>	<p>Of the 36 individual studies reviewed, 11 were grade I (highest level of evidence and included Cochrane Reviews, RCTs), 14 grade II (surveys), and 11 grade III (focus groups, case studies, pilot projects).</p> <p>Researchers found that multifaceted education (e.g., use of various media), and those that are personally tailored are most effective. Findings from studies graded I suggest that a combination of oral presentation and written information (e.g., pamphlets or ‘written action plan’) is most effective.</p>
<p>Coventry (2005) * Systematic review to identify tools and predictor variables that might help clinicians estimate survival and assess palliative status in non-cancer patients aged 65 years and older.</p> <p>Three studies reported disease-specific prognostic models, two reported generic prognostic models, three evaluated predictor variables for short-term (≤ 6 months) survival in dementia patients and three evaluated predictor variables for longer-term survival (≤ 5 years) in chronic obstructive pulmonary disorder (COPD).</p>	<p>11 studies (10 cohort studies and 1 retrospective analysis of 2 randomized trials)</p>	<p>inpatient, nursing home, home- and institutional-based hospice, and outpatient settings were included</p>	<p>Key generic predictors of survival were increased dependency of activities of daily living, presence of comorbidities, poor nutritional status and weight loss, and abnormal vital signs and laboratory values. Disease-specific predictors of survival were identified for dementia, chronic obstructive pulmonary disorder and congestive heart failure</p>	<p>Of the 11 studies, 5 were graded “good” (A), 4 grade B, and 2 grade C.</p> <p>Disease-specific prognostic models The SUPPORT model had poor positive discrimination when applied to the group that incorporated COPD, CHF and ESLD patients. The (US) National Hospice Palliative Care Organization (NHPCO) guidelines for determining prognosis in non-cancer diseases were similarly ineffective in predicting ≤ 6 month survival in a group of SUPPORT patients with COPD, CHF and ESLD:</p> <p>Generic prognostic models Only one (grade B) study measured the ability of a dedicated prognostic tool to improve end-of-life clinical decision making in patients</p>



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				<p>with non-malignant disease. At the end of the study, >60% of all patients had died within a month; agreement between CPS and actual survival was moderate (=0.59).</p> <p>No prognostic model presented in this review can be recommended for routine clinical use without further validation.</p>
<p>Francke (2000) * Systematic review of the effectiveness of palliative care support teams.</p> <p>Palliative support teams give advice about palliative care and often also practical help, on request, to patients or care providers. Most teams also support relatives.</p> <p>The teams studied all employed a multidisciplinary approach: the core all cases consisted of nurses, often closely collaborating with physicians and sometimes also with pastoral and social workers and paramedics. All teams were either hospital-based or connected to community care organizations.</p>	<p>16 studies (6 controlled trials, 1 RCT, and 10 uncontrolled)</p>	<p>Hospital-based or community care organizations</p>	<p>In 10 of the 16 studies, pain or other physical complaints were used as outcomes. In seven of the 16 attention is also paid to psychosocial and spiritual problems of the patient and their relatives. Five studies addressed health care consumption.</p> <p>Outcomes of palliative care including self-reported effects on symptoms and problems of from patients and/or their relatives, consumption and cost of health care, and survival rates</p>	<p>In the studies that addressed pain and other physical complaints, positive results were reported. The exception was the single RCT, which found no difference (although the authors attribute this to a high number of non-responders).</p> <p>The studies that addressed psychosocial and spiritual complaints, were generally more mixed (e.g., several cases of no significant improvement or much greater improvement in physical symptoms).</p> <p>The authors concluded that palliative care teams are most effective in treating pain and physical symptoms and effective to a lesser degree in addressing psychosocial and spiritual problems.</p>

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<p>Harding (2003) * Systematic review of the literature regarding interventions to support informal caregivers of noninstitutionalized patients with cancer and provide palliative care.</p> <p>Interventions included: home nursing care (four), respite services (three), social networks and activity enhancement (two), problem solving and education (three) and group work (10). Of these, nine were delivered solely to carers (i.e., were targeted services).</p>	<p>22 papers related to interventions in cancer and palliative care which included/ targeted carers.</p> <p>Of these 22, nine were services specifically for carers, and six had been evaluated.</p>	<p>Noninstitutionalized patients with cancer and palliative care needs</p>	<p>Key outcomes included satisfaction, quality of life, emotional/social/physical functioning for the carer</p>	<p>Of the 22 interventions, nine were delivered solely to carers. Only six of the carers’ interventions had been evaluated, two of these had used a randomized control trial (RCT; grades IB), three employed a single group methodology (two prospective grades IIIC and one retrospective grade IIIC) and one was evaluated using facilitator feedback.</p> <p>Overall, a lack of rigorous outcome evaluations was reported. The current evidence contributes more to understanding feasibility and acceptability than to effectiveness.</p>
<p>Hearn (1998) * Systematic literature review of published research to determine whether teams providing specialist palliative care improve the health outcomes of patients with advanced cancer and their families or carers when compared to conventional services.</p>	<p>18 studies including 5 RCTs</p>	<p>Hospital, hospice and community settings</p>	<p>Improved outcomes seen in amount of time spent at home by patients, satisfaction by both patients and carers, symptom control, reduction in number of inpatient hospital days and overall cost, and patients’ likelihood of dying where they wished - those receiving care from a multiprofessional palliative care team</p>	<p>When specialist multiprofessional care is compared to conventional care, four of the five RCTs and the majority of the comparative studies indicate that the specialist, coordinated approach resulted in similar or improved outcomes. The results presented from the successful studies support the use of specialist multiprofessional teams in palliative care to improve satisfaction of both the patient with advanced cancer and their family or carers. Those studies, which examined costs, showed a tendency for a reduction in hospital inpatient days, more time spent at home, and equal or lower costs.</p>


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<p>Higginson (2003) * Systematic review and meta analysis to determine the effectiveness of palliative and hospice care teams (PCHCT).</p> <p>Palliative care and hospice team defined as two or more health care workers, at least one of whom had specialist training or worked principally in palliative or hospice care) as compared to “usual care”(defined as routine community or general hospital/oncology services).</p>	<p>44 studies meeting inclusion criteria. Meta regression was conducted for 26 of the studies and a meta analysis with 19 of the studies. Economic analysis was conducted on 14 studies</p>	<p>22 of the 44 studies assessed home care teams, 9 hospital based teams, 4 combined home and hospital teams, 3 in-patient units, and 6 integrated in-patient hospice care with either home or hospital teams as part of a larger service</p>	<p>For patients: pain, other symptoms, quality of life, satisfaction, referral to other services, and therapeutic interventions (usually adherence to prescribing or other guidelines). For caregivers the outcomes were: pre-bereavement burden/morbidity, post-bereavement burden/morbidity, pre-bereavement satisfaction, and post-bereavement satisfaction</p>	<p>Much evidence was of moderate/poor quality. Most studies were grade III (retrospective, observational, cross sectional), and the grade II (prospective with comparison or retrospective with controls) or I (RTC/RCT review) were often flawed.</p> <p>Meta regression (26 studies) found slight positive effect, of approximately 0.1, of PCHCTs on patient outcomes, independent of team make-up, patient diagnosis, country, or study design.</p> <p>Meta analysis (19 studies) demonstrated benefit on patients’ pain (odds ratio [OR]: 0.38, 95% confidence interval [CI]: 0.23–0.64), other symptoms (OR: 0.51, CI: 0.30–0.88), and a non-significant trend towards benefits for satisfaction, and therapeutic interventions.</p> <p>Meta synthesis (44 studies) found wide variations in the type of service delivered by each team; One of the most consistent effects was of improved satisfaction for caregivers and, to a lesser extent, for patients. This finding was strongest for home care services—where most studies were found.</p> <p>Economic studies (14 studies) Only one study provided full economic cost-benefit evaluation. Among the other 13 which evaluated cost but not effectiveness, there was some evidence to suggest substitution</p>


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				between hospital and home care, reducing the number of inpatient days, and hence costs of health care.
<p>Jezewski (2007) * Systematic review to determine effectiveness of didactic and interactive interventions to increase advance directive (AD) completion rates.</p>	<p>25 studies meeting inclusion criteria</p> <p>Of the 25 studies reviewed, 14 were experimental studies group).</p>	<p>Community-dwelling, institutionalized participants, and participants from a health maintenance organization</p> <p>Of the 25 studies reviewed, 14 studies recruited participants aged 50 years and older, and 10 of the studies included participants aged 16 years and older. In the final study, demographics were not presented</p>	<p>AD completion rates although attainment of legal execution of the documents was not verified</p>	<p>The success of the interventions to increase AD completion varied considerably across studies.</p> <p>The AD completion rates for didactic studies ranged from no change to a 34% increase in AD completion postintervention. For interactive type studies, the AD completion rate postintervention ranged from 23% to 71%. These studies illustrate that AD education without the ability to ask questions does not significantly increase AD completion rate. For didactic studies, the increase in completion rates was usually no higher than the predicted average completion rate for the general population (below 20%). Interaction with a knowledgeable resource person and the opportunity to discuss individual concerns seem to be critical to an intervention's effectiveness. Furthermore, interventions that were most effective included repeated contacts or stimuli toward AD completion.</p>



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<p>Kass-Bartelmes (2003) This literature review published by the Agency for Healthcare Research and Quality (AHRQ) synthesizes evidence related to advance care planning highlighting evidence-based practice.</p>	<p>A total of 48 articles, of unknown quality and methodology are referenced by these authors</p>	<p>Not stated (variety of settings implied)</p>	<p>Patient preferences for care at end of life</p>	<p>AHRQ research shows that care at the end of life sometimes appears to be inconsistent with the patients’ preferences to forgo life-sustaining treatment and patients may receive care they do not want. According to patients who are dying and their families who survive them, lack of communication with physicians and other health care providers causes confusion about medical treatments, conditions and prognoses, and the choices that patients and their families need to make. Research suggests a five-step process be adopted by physicians for discussions with patients about advance directives: guided discussion, sharing information about advance directives and durable power of attorney, completion of documents, regular review of patient preferences and updating of information.</p>
<p>Kwak (2005) Literature review on racial and ethnic diversity and end of life decision making.</p>	<p>Examination of 33 empirical studies</p>	<p>Community, senior centers, managed care, nursing homes, clinics, inpatient and outpatient settings</p>	<p>Advanced care planning, life support, communications about diagnosis and prognosis, and role of the family in decision making</p>	<p>Possession Whites were more likely to have some form of advance directive than African Americans. Hispanics, Asians, Native Americans. Knowledge In 4 of 5 studies, Whites were found to be more knowledgeable about advance directives. Attitudes (7 studies)</p>

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				<p>African Americans are more likely to have negative attitudes about advance directives. Findings suggest that there are culture-specific attitudes that make the concept of advance directives problematic or unappealing.</p> <p>Use of life support Older African Americans are more likely to choose life sustaining measures than their White counterparts. Asians and Hispanics were more likely to prefer family-centered decision making.</p> <p>Diagnosis/prognosis preferences (5 studies) Cultural differences clearly exist in terms of preferences about who should be told about the diagnosis/prognosis</p> <p>Designation of primary decision maker Family involvement was important among all racial/ethnic groups.</p>
<p>Lorenz (2008) * Based on the Agency for Healthcare Research and Quality (AHRQ) Evidence Practice Report on end of life (2004)</p> <p>Review covers treatment strategies for pain, dyspnea, and depression including pharmacologic and complementary and</p>	<p>Overall report includes 33 high-quality systematic reviews and 89 intervention reports selected by a Technical Expert Panel.</p>	<p>Various (e.g., home care, hospital based, and hospice)</p>	<p>Various outcomes including symptoms; quality of life; physical function, satisfaction with care; knowledge; place of care and site of death; and utilization, knowledge recall, understanding, ,</p>	<p>Depression Strong evidence supports psychotherapy, as well as tricyclic antidepressants and SSRIs, for depression treatment in cancer.</p> <p>Dyspnea Strong evidence supports treating dyspnea with β-agonists and opioid use in COPD, although these trials are small and short in duration.</p>

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alternative medicine treatments and care delivery interventions (e.g., palliative care teams).			psychological well-being, patient, caregiver, and provider, mortality; readmission; disability; communication	<p>Pain Strong evidence supports approaches to treating cancer pain with nonsteroidals, opioids, radionuclides, and radiotherapy. Moderate evidence supports multicomponent interventions to increase advance directives; however, such studies seldom measure clinically important outcomes.</p> <p>Utilization Moderate evidence supports multidisciplinary interventions that target continuity to affect utilization outcomes.</p> <p>Caregiver Support Weak to moderate evidence suggests that caregiver interventions, especially when comprehensive and individually targeted, can improve various measures of caregiver burden, although effect sizes are small.</p>
<p>Mezey (2002) The authors explore the literature describing the quality of life at the end of life and quality of dying among vulnerable older adults in different settings</p>	Review of the literature. The cited evidence is of unknown quality and methodological rigor	Evidence review was conducted and documented by setting (i.e., home, assisted living, skilled nursing home, prison)	Pain and symptom management	<p>Pain</p> <ul style="list-style-type: none"> The authors generally report trends of under medication by patients, family members, and paid staff because of fear of addiction, hastening the dying process, and issues with ordering and/or dispensing. <p>Nutrition/hydration</p> <ul style="list-style-type: none"> The authors acknowledge a dearth of evidence on nutrition preferences, support, and management. The authors report that caregivers are far


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				<p>less likely to forgo tube feedings than CPR for dying older patients</p> <p>Dyspnea</p> <p>No evidence was found to address dypnea management in vulnerable older adults.</p>
<p>National Quality Forum (NQF; 2006) +</p> <p>Based on the National Consensus Project for Quality Palliative Care’s (NCP’s) <i>Clinical Practice Guidelines for Quality Palliative Care</i>, NQF endorsed 38 preferred practices suitable for implementation by palliative care and hospice programs. The practices are based on published studies or widely accepted experiential information.</p>	<p>Preferred practices derived by consensus and supported by evidence or widely accepted experiential information</p>	<p>Palliative care and hospice programs</p>	<p>The aim of these consensus-based preferred practices is to ensure that palliative care and hospice services are of the highest quality</p>	<p>The NQF-endorsed preferred practices address:</p> <p>access and/or referral (2 preferred practices); care planning and coordination (11); decision making (7) patients/families/caregivers (9); specialist care (4); symptom management (6)</p>
<p>Pan (2000) *</p> <p>Systematic review of the efficacy of complementary and alternative medicine (CAM) modalities in treating pain, dyspnea, and nausea and vomiting in adult patients with incurable conditions/near the end of life.</p> <p>Interventions evaluated included:</p>	<p>21 studies; of these, 11 were randomized controlled trials, two were non-randomized controlled trials, and eight were case series</p>	<p>Unknown</p>	<p>Fourteen studies addressed pain, six evaluated dyspnea, and one was on nausea and vomiting. Outcomes included quality of life, mobility, and perceived pain, breathlessness, and nausea</p>	<p>The review concludes that the following interventions may provide pain relief in cancer pain or in dying patients: Acupuncture, TENS, Relaxation/imagery can improve oral mucositis pain.</p> <p>The following interventions may provide benefit to patients with severe chronic obstructive pulmonary disease:</p>

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transcutaneous electrical nerve stimulation (TENS), acupuncture and acupressure, massage (w/ and w/out aromatherapy), psychologic therapies, music therapy, breathing training).				<p>Acupuncture Acupressure muscle relaxation with breathing retraining to relieve dyspnea , Psychoanalysis</p> <p>Despite the paucity of controlled trials, there are data to support the use of some CAM modalities in terminally ill patients.</p>
<p>Parker (2007) * Systematic review to determine effectiveness of prognostic/end of-life communication with adult patients in the advanced stages of a life-limiting illness and their caregivers.</p>	<p>123 articles (99 studies) and 46 articles reported on patient/ caregiver preferences for content, style, and timing of information.</p>	<p>Patients in specialist palliative care or hospice settings (inpatient or community) or patients in any care setting with a diagnosis of advanced life-limiting illness being treated with palliative intent and with a life expectancy of less than two years</p>	<p>Patient/Caregiver preferences for content, style, and timing of prognostic information</p>	<p>Forty-four of the 46 studies reporting patient and/or caregiver preferences for the content, style, and timing of prognostic/EOL information were rated as Level IVa evidence and one study as Level II (evidence obtained from at least one properly designed, randomized controlled trial).</p> <p>Although there were individual differences, patients/caregivers in general had high levels of information need at all stages of the disease process regarding the illness itself.</p> <p>In general, most patients/caregivers wanted at least some discussion of these topics at the time of diagnosis of an advanced, progressive, life-limiting illness, or shortly after. However, they wanted to negotiate the content and extent of this information.</p>


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<p>Salisbury (1999) * Systematic review to determine the impact of alternative models of specialist palliative care on the quality of life of patients.</p>	<p>83 articles which included 22 descriptive studies and 27 comparative studies (the focus of the authors' review)</p>	<p>Various settings including hospital, hospice, and home</p>	<p>Various outcomes including patient satisfaction, quality of life, and cost</p>	<p>There was some evidence that inpatient palliative care provided better pain control than home care or conventional hospital care, but this research was dated and open to criticism. Research on palliative home care teams and coordinating nurses has demonstrated limited impact on quality of life over conventional care for patients dying at home.</p> <p>The overall conclusion must be that there is little robust evidence that any form of organization of specialist palliative care offers significant advantages in terms of the impact on patients' quality of life.</p>
<p>Thomas (2005) * A systematic review of randomized controlled trials (RCTs) of non-medical and non-surgical therapies for palliative care to provide guidance for best practice palliative care.</p> <p>The following therapies/interventions were evaluated: acupuncture, aromatherapy, breathing training, hypnosis, massage, multisensory stimulation, music therapy, psych/behavior therapy, reflexology, therapeutic touch.</p>	<p>15 RCTs</p>	<p>Various settings including hospital, hospice, palliative care unit</p>	<p>Varied intervention and outcome measures including physical and psychological functioning, medication use, quality of life, length of stay, readmission rates, and survival</p>	<p>The methodological quality of many of the 15 RCTs did not meet most of the Cochrane Collaboration methodological criteria, resulting in a high risk of bias in most of the currently available RCT studies.</p> <p>Several studies found positive results but the sample sizes were small, the methodological quality of the RCTs did not meet Cochrane Collaboration criteria, and the conclusions were at high risk of bias.</p>


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<p>Wenger (2001) + The authors describe the process for developing 14 validity-assessed quality indicators for end of life care in vulnerable older adults (ACOVE).</p>	<p>Indicators were developed using a process that was both evidence-based and consensus driven</p>	<p>Various settings including hospital, nursing home, and outpatient</p>	<p>ACOVE indicators are intended to assess the provision of care to achieve a “good death” (e.g., one that is free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards; IOM, 1997)</p>	<p>Four ACOVE quality indicators address symptom management: Nine ACOVE quality indicators address patient decision making: One ACOVE quality indicator addresses family support:</p>
<p>Wilkinson (1999) * Systematic literature review examined the impact of specialist models of palliative care on consumer satisfaction, opinion and preference.</p>	<p>83 studies</p> <p>Interview studies; retrospective interview studies; observational studies; questionnaire surveys</p>	<p>Various settings for comparison (e.g., inpatient hospice care, nonspecialized care, specialized community care)</p>	<p>Consumer opinion and satisfaction</p>	<p>Research findings from North America did not reveal any reliable or consistent trends, and this was due primarily to methodological flaws in the research. In the UK, consumers are more satisfied with all types of palliative care, whether provided by inpatient units or in the community, than with palliative care provided by general hospitals.</p>
<p>World Health Organization (2004) + A summary of evidence for health policy- and decision-makers summarizing the needs of older people, the different trajectories of illnesses, evidence of underassessment of pain</p>	<p>Synthesis of findings from research in the European community and recommended end of life practices. The cited evidence is</p>	<p>Unknown</p>	<p>Preferences for place of care</p>	<p>No evidence that demonstrates that advance directives are followed, or influence use of resources or cost. Specialist palliative care teams have been found to control pain and improve satisfaction among patients and family members.</p>

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and other symptoms, patient’s need to be involved in decision-making, evidence for effective palliative care solutions, and issues for the future.	of unknown quality and methodological rigor.			<p>Development of multidisciplinary palliative care for non-cancer patients (e.g., heart failure, dementia), with particular emphasis on specialist nurses, has shown some benefit. Skills of individual health care professionals should include pain and symptom control, communications, and provision of information.</p> <p>Provision of holistic care should include spiritual and religious support, psychological support (e.g., adjunct psychological therapy), and complementary therapy.</p> <p>To satisfy preferences, coordinating care between settings and providers enables more patients to die at home. A variety of approaches to support informal caregivers (e.g., respite, support groups) have been developed and often lead to improved satisfaction.</p> <p>Generally, the authors acknowledge mixed and/or inconclusive evidence supporting these practice recommendations.</p>
Zimmerman (2008) * Systematic review of studies evaluating the effectiveness of specialized palliative care services.	22 RCTs evaluating the effectiveness of specialized palliative care services	Various settings including home, hospital, nursing home, and outpatient	Quality of life, satisfaction with care, health care use (ER visits, length/number of	The authors conclude there is little evidence to support specialized palliative care for patients with terminal illness based on impact on quality of life, health care use, and

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			hospitalizations, use of hospital resources, advance care planning, referral to hospice, death at home, time at home), and economic cost	economic cost. Of these outcomes, most consistent evidence for effectiveness of specialized palliative care in improvement of family satisfaction with care (7 of 10 studies)

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