

Chapter 4. Research Recommendations

Overview

Our literature review identified a very large and diverse body of literature reflecting the tremendous growth and importance of the field of end-of-life care over the last decade. This review of the scientific evidence underlying key parts of the field of end-of-life care illuminates strengths of the field as well as opportunities for research. We identified evidence supporting the association of satisfaction and quality of care with pain management, communication, practical support, and enhanced caregiving. The literature review identified evidence to support the effectiveness of interventions to improve satisfaction, ameliorate cancer pain, and relieve depression in cancer; non-pharmacologic interventions for behavioral problems in dementia; and interventions to foster continuity in cancer and CHF care. Evidence is strongest in cancer, reflecting progress in acknowledging the place of palliative care in the research agenda and clinical practice of oncology.

Limitations

Several issues related to the nature of the literature complicated this review.

- An important challenge at the present time is the lack of a settled definition of the “end of life.” Although our review worked with the broadest definition, any choice would be unsatisfactory because the definitions in the literature are inconsistent and inexplicit. In addition, much of the literature on advanced stages of fatal illnesses is not indexed as “end of life,” thus making it difficult to include in a broad review.
- We observed a lack of clarity concerning certain concepts and their measurement. One example was satisfaction, but the same issues affect other topics, a fact that hindered our ability to classify outcomes and their relevance to patients and families.
- Most of the literature in end-of-life care does not clearly describe and compare the characteristics and outcomes of groups of patients. Therefore, this review was not able to explore many of the distinctions among patient groups, such as those affected by cancer, CHF, or dementia.
- We found it necessary to focus on selected data sources and topics. We utilized various strategies to incorporate most of the articles that the field itself identifies as very relevant at this time, such as reviewing references of the National Consensus Project and systematic reviews. We were unable to include many symptoms, such as delirium or fatigue, that may be even more common than those we highlighted. Similarly, we did not review bereavement, spirituality, or other specific outcomes including functional status or length of survival. We also did not evaluate cost of care, although it has obvious distributive implications and is a significant societal concern as our population ages.
- These same considerations led to our exclusion of clinical trials of palliative chemotherapy, radiotherapy, stents, laser therapy, and other technically complex care. The omission of these topics, which can have major impact on palliation, suggests that there may be need for in-depth review of these areas to guide future palliative care practice. Costly and medically complex care such as implanted cardioverter defibrillators,

biventricular pacing, and ventricular assist devices also increasingly characterize care for advanced CHF, and understanding the risks and benefits of such procedures vis-à-vis palliation is extremely important, although also out of scope of our review.

- To understand associations, our review focused on the highest-quality evidence (e.g., randomized clinical trials, intervention studies, and prospective cohort observational studies) to examine whether certain patient (e.g., race/ethnicity, disease) or healthcare system (e.g., site of care) factors are associated with better or worse outcomes of palliative care. By not being able to review all observational studies, we may well have missed some important associations among patient, family, and healthcare system factors and outcomes. We also did not include nonsystematic efforts, such as clinical practice guidelines and consensus documents, and therefore have not included recommendations based on expert consensus.

Given these choices and parameters, we identified important research opportunities for the field. In this section, we focus first on the lack of a definition of the “end of life” population (Preliminary Question), then on gaps in evidence related to conceptualizing and measuring satisfaction and other outcomes relevant to patients and caregivers (Question 1). We offer conclusions related to understanding variations (Question 2) and the effectiveness of interventions (Question 3) to improve each of the specific outcomes we addressed in this report.

Definition of the “End-of-Life” Population Needed

The lack of consensus on the definition of “end of life” leaves what various researchers have called “the denominator problem.” If one aims to reduce the rate of dyspnea, for example, one must have a stable, replicable, and meaningful definition of the population. In a previous review of this literature, George also observed the lack of a consistent conceptual and operational definition of end of life.²¹ The undefined nature of the category is apparent in the widely varying populations in studies we identified. We examined substantial numbers of reports of prognostic modeling (see Appendix A) and found that this literature does not and probably cannot define a population that both includes most people suffering with fatal illnesses and includes them only for a short time (e.g., six months before death).

The correct definition of end of life may well depend upon what use is to be made of the definition. If the purpose involves public policy for a diverse array of patients with various serious illnesses and social situations and if the aim is to identify opportunities for tailoring services to match the needs of most of the group, the definition will need to encompass many very seriously ill people and will necessarily include some patients who live a long time. If the use involves securing care for the last hours of life, the definition will be much more narrow. Similarly, if the definition is meant to signal authorization for physician-assisted suicide, the tolerance for errors of over-inclusion will be small. For research purposes, a few clear definitions of the scope might well be enough to allow clear reporting of the denominator population for each study and to enable comparisons across time and setting.

We identified relatively few studies (especially studies in hospice or palliative care settings) that made clear distinctions or studied distinct categories of illness; even fewer studies set out to compare the end-of-life experience of various conditions. The patient and family experience of the end of life has been best described in cancer. Very few studies address even the most important end-of-life symptoms in non-cancer conditions, despite the fact that the few existing

studies suggest the importance of separately considering conditions, or perhaps major groupings of conditions. In the lives of many patients, of course, conditions occur together, and there is a separate need to understand how multiple comorbidities affect the end-of-life experience. Finally, attention to particular conditions would emphasize the extent to which the end of life is being affected by treatment innovation such as the proliferation of technologies in CHF treatment. For these reasons, we suggest:

- *Consideration 1: Research is needed to characterize the implications of alternative conceptual and operational definitions of the “end of life,” particularly for important conditions. Efforts are needed to define populations with specific unmet palliative care needs.*

Measures and Satisfaction with Care and the End-of-Life Experience

The field has made a promising beginning in developing sound tools for evaluating end-of-life care, but gaps in the availability of measures remain. While some instruments have been evaluated in cancer and mixed populations in which cancer predominates, few instruments have been tested in prevalent non-cancer conditions. Related methodological issues include assessing patients with cognitive impairment and better understanding the limitations of proxy response. Novel approaches to evaluating outcomes may be needed in certain populations, and the limits of observation and self-report need examination.³⁷⁵ Indeed, a number of methodological challenges in end-of-life research need sustained attention. In addition to the problem of substitute respondents, the challenge of the variable timing of death and its effect upon measurement needs attention.

Whether measures respond to changes in care system performance has not generally been tested, and only a few of the most rigorously developed instruments have been tested or applied in different settings. The experience of health care differs among settings and, according to evidence we identified in reviewing satisfaction, by disease or by the nature of the caregiver’s relationship with the patient. Thus, researchers need to develop specific tools depending on the research objectives, or at least to account for potential differences in their analyses when evaluating the effectiveness of palliative care interventions. High-quality studies generally have not yet addressed the experience of health care while dying from different cultural perspectives, but adapting existing instruments and evaluating differences will be important as our aging population becomes more diverse.

With regard to satisfaction, we noted that most studies do not offer any conceptualization of satisfaction, and there is much overlap among instruments that measure satisfaction and other aspects of end-of-life care. Indeed, satisfaction has some limitations as a measure of care performance. Most studies of satisfaction did not employ standardized instruments, or if they did, they are often instruments that were not specifically developed for end-of-life settings or that reflect the kinds of healthcare experiences that are specific to the end of life. Important differences in the experience of health care are suggested by disease trajectory and by caregiver perspective, and the importance of measuring specific attributes of medical care is suggested by the fact that studies that observe differences in satisfaction have often done so in the context of instruments that include detailed items rather than simple summary measures. Better understanding is needed of the relationship of satisfaction to treatment of symptoms other than

pain, spiritual support, continuity and coordination of care, in particular. For these reasons, we recommend:

- *Consideration 2: Further measure development should emphasize testing the highest-quality measures in important settings (e.g., hospital, nursing home, hospice, and ambulatory care). These measures need to be evaluated in diverse populations (e.g., racial/ethnic groups, non-cancer conditions). Measures would benefit from being standardized for comparisons among studies.*
- *Consideration 3: Studies evaluating satisfaction should use specific measures that reflect processes of care, and studies should examine the relationship of satisfaction to less-studied processes such as non-pain symptoms, spiritual support, and continuity.*
- *Consideration 4: Methodological challenges in measurement require focused research. Strengthened research infrastructure including collaborative networks should be considered.*

Pain, Dyspnea, Depression and Anxiety, and Behavioral Symptoms in Dementia

The preponderance of the evidence we reviewed supports the effectiveness of pharmacologic and system interventions for cancer pain. Nevertheless, the stability of population rates of cancer pain presents a caution; having evidence from interventional research that showed effective relief of cancer pain in substantial populations would be most useful. More rigorous studies are needed to understand the use of non-pharmacologic therapies and how they should be combined or sequenced with pharmacologic therapies. Limited evidence is troubling in that it suggests that pain characterizes a variety of severe illnesses, but studies are needed to characterize both the basic epidemiology and the clinical interpretation of pain in non-cancer conditions.

With regard to dyspnea, some evidence supports the efficacy of a variety of pharmacologic and non-pharmacologic interventions to reduce dyspnea in cancer and non-cancer conditions. Studies of opiates have been promising, although these studies are small and heterogeneous. The basic epidemiology and clinical interpretation or meaning of dyspnea in cancer and non-cancer conditions need to be better described. As with other symptoms, research on implementation of known better practices remains a priority.

With regard to depression and anxiety, and behavioral symptoms in dementia, the preponderance of evidence supports the effectiveness of pharmacologic interventions for depression in cancer; however, few of these studies focused on patients with later-stage cancer or in palliative care clinical settings. A variety of studies support the efficacy of non-pharmacologic interventions. We also need to understand the sequencing and combining of pharmacological and non-pharmacological therapies. In addition, the research to date does not adequately characterize the merits of controlled environments, environmental stimulation, and medication in ameliorating behavioral symptoms. These observations give rise to the following recommendations:

- *Consideration 5: Symptoms have been relatively well characterized in cancer, but high-quality studies of the incidence and epidemiology of pain and other symptoms, the relationship among symptoms, and the clinical significance of symptoms are needed in non-cancer conditions.*
- *Consideration 6: Small, high-quality studies suggest the effectiveness of interventions to alleviate dyspnea. Larger studies of interventions to alleviate dyspnea in cancer and non-cancer conditions are needed.*
- *Consideration 7: Studies that evaluate short-term as well as longer-term treatment of depression in palliative care settings are needed.*

Caregiving

With regard to caregiving, we noted a lack of intervention outcome evaluation designs and a reliance on intervention descriptions and formative evaluations in the literature. Caregiver outcome studies suffer from small sample sizes and the predominant use of convenience samples. Many studies were non-randomized and characterized by sampling homogeneity (e.g., little diversity in the characteristics of caregivers and care receivers). Interventions vary widely and caregivers were rarely screened prior to study entry for problems or need related to the specific intervention being tested or the measured outcomes. There is confusion in the field concerning the operationalization and measurement of major caregiver outcomes, diversity in length, duration, and intensity of specific interventions strategies. In addition, a better match between interventions and outcomes is needed. There was also little research to systematically evaluate variability in cultural expectations of care.

Methodological challenges in studying these interventions may mean that alternatives to randomized controlled trials should be welcomed as the best available data. Most caregiving literature has found that, while caregivers rate interventions favorably, objective and subjective indicators of overall burden show little change. It is critical to identify specific outcomes most likely to be changed by the intervention employed. Burden may be too global and multidimensional to be affected by interventions because it has both subjective and objective qualities and there is a lack of conceptual clarity about what actually differentiates the subjective from the objective.³⁷⁶ Measures of objective burden often ask the respondent how they “feel” about a particular caregiving situation or the impact of caregiving. Many measures of burden may not sufficiently differentiate between objective tasks and feelings about the experience of caregiving.

Future research in family caregiving needs to increase sample sizes and homogeneity. Attention is also needed to determine whether standardized or individualized interventions produce the best outcomes in family caregivers. Theoretically, those interventions linked to caregiver needs should produce the best outcomes, but this idea must be tested and validated or refuted. Researchers must also evaluate the optimal length, duration, and intensity of specific intervention strategies. Researchers must select outcomes that are likely to be changed by the intervention being tested. Caregiver research must also account for financial and social effects of caregiving upon the caregiver and the family, and the societal vision of optimal family caregiving is itself worthy of research, especially regarding cultural expectations of care.

- ***Consideration 8: Limited research supports the effectiveness of interventions for cancer and dementia caregiving. High-quality studies in other populations are needed. These studies need to pay special attention to such methodologic issues as careful sample selection and measurement of specific outcome variables that reflect intervention aims.***
- ***Consideration 9: The economic and social dimensions of caregiving need additional research.***

Continuity of Services

The models of service delivery that yield optimal outcomes for patients and families are not yet clear. Research on integrated delivery models, such as PACE and hospice, have been descriptively useful, but well-controlled studies are rare. Research on primary care and simple continuity has not generally examined patients so sick as to be at the end of life. Our review provided limited evidence for the ability of interventions to improve what we have designated as management continuity at the end of life—partly, this may be related to the measures used, which are often focused on such indirect outcomes as site of death. We found more evidence for the ability to improve continuity of care related to communication.

Studies of continuity in CHF are very promising, and successful approaches to fostering continuity in CHF share some important features with multi-component palliative care interventions. Despite the strengths of this literature, limitations in the interventions, measures, and exclusionary criteria that characterize these studies restrict their usefulness in understanding how to achieve palliative goals for these patients. Studies that incorporate these considerations are needed to broaden our understanding of how to serve the sickest patients with CHF and similar conditions. Our recommendations include:

- ***Consideration 10: Substantial evidence supports interventions to improve continuity between home and hospital. Continuity research needs to look at other settings in which most patients are cared for—e.g., ambulatory care. Additional study of nursing home–hospital continuity and studies that incorporate multiple settings and providers are needed.***
- ***Consideration 11: Studies of continuity in CHF and other conditions should incorporate the palliative domains described above (e.g., physical and psychological symptoms, caregiver burden, advance care planning) and need to be more generalizable to the sickest patients. Such studies need to include patients with multiple comorbidities.***

Advance Care Planning

A fully informative research base would address the plausibility and outcomes of making advance care plans for future clinical scenarios for a diverse array of patients and would evaluate the optimal approach to implementing care system processes that yield better outcomes. The reported experience in La Crosse and the Veterans Health System suggests that it might be possible to document advance directives more commonly. However, advance care planning was associated with only minor changes in ICU time or costs and with no effect in the few RCTs that have addressed the issue. Most studies of the effectiveness of advance care planning are negative, studied small samples in one site, and are several years old.

The clinical situation often seems to call for anticipating what might otherwise be harmful complications, rather than to call for advance care planning as an expression of autonomy. But does considering future complications and the expected worsening of health benefit patients and families? Can it be done in a reasonable time, can decisions and plans be implemented over time and across settings? The generally lackluster performance of advance directives and advance care planning leads some to question whether alternative approaches to reducing the use of certain high-intensity treatments might be evaluated, at least in some circumstances. For example, rather than having every patient and family with early dementia document a decision about artificial feeding, it may be better to assume that patients with advanced dementia should not get a feeding tube unless the patient or family actively seek such treatment. Or it may be that improving advance care planning requires widespread community activation, as in the example of Oregon.

However, alternative approaches to advance care planning might have unanticipated effects. For example, will patients and families also be less informed about diagnosis and prognosis? Would certain approaches affect the ability of patients and families to engage in practical planning for family support and caregiving? The persistently limited success of advance care planning as shown in limited research also calls out for reevaluating more fundamental assumptions—such as that the future is largely shaped by decisions, that those decisions generally can be examined in terms of optimizing outcomes, that people have important and persistent preferences among the possible outcomes, and that they are willing to articulate decisions and abide by them.

- ***Consideration 12: Rigorous research in advance care planning is needed to understand how to best achieve patient and family goals (as opposed to evaluating resource allocation), and such research needs to address fundamental processes of care planning.***

Reference List

1. Hogan C, Lynn J, Gabel J, Lunney J, Mara A, Wilkinson A. Medicare beneficiaries' costs and use of care in the last year of life. Washington, DC: The Medicare Payment Advisory Commission. 2000.
2. Center for Disease Control. Deaths: Preliminary Data for 2002. <http://www.cdc.gov/nchs/releases/04news/infantmort.htm>. Accessed February 18, 2004.
3. Institute for the Future. Health and Healthcare 2010: The Forecast, The Challenge. Princeton, NJ: Jossey-Bass; 2003.
4. Kaye S, LaPlante MP, Carlson D, Wenger BL. Trends in disability rates in the United States, 1970-1994. Washington, DC: U.S. Department of Health and Human Services. 1996.
5. Anderson G, Horvarth J, Anderson C. Chronic conditions: Making the case for ongoing care. Baltimore, MD. 2002.
6. Freedman VA, Aykan H, Martin LG . Aggregate changes in severe cognitive impairment among older Americans: 1993 and 1998. *J Gerontol B Psychol Sci Soc Sci* 2001 ;56(2):S100-11.
7. Freedman VA, Martin LG. Understanding trends in functional limitations among older Americans. *Am J Public Health* 1998;88(10):1457-62.
8. Gill TM, Desai MM, Gahbauer EA, et al. Restricted activity among community-living older persons: incidence, precipitants, and health care utilization. *Ann Intern Med* 2001;135(5):313-21.
9. Fried LP, Guralnik JM. Disability in older adults: evidence regarding significance, etiology, and risk. *J Am Geriatr Soc* 1997;45(1):92-100.
10. Sharma R, Chan S, Liu H, Ginsberg C. Health and health care of the Medicare population: Data from the 1997 Medicare current beneficiary survey. Rockville, MD: Westat. 2001.
11. Manton KG, Corder LS, Stallard E. Estimates of change in chronic disability and institutional incidence and prevalence rates in the U.S. elderly population from the 1982, 1984, and 1989 National Long Term Care Survey. *J Gerontol* 1993;48(4):S153-66.
12. Carter GT, Bednar-Butler LM, Abresch RT, et al. Expanding the role of hospice care in amyotrophic lateral sclerosis. *Am J Hosp Palliat Care* 1999;16(6):707-10. Comment in: *Am J Hosp Palliat Care*. 1999 Nov-Dec;16(6):696-7. PMID: 11094904.
13. Cornoni-Huntley JC, Foley DJ, White LR, et al. Epidemiology of disability in the oldest old: methodologic issues and preliminary findings. *Milbank Mem Fund Q Health Soc* 1985;63(2):350-76.
14. U.S. Census Bureau. Projections of the resident population by age, sex, race, and Hispanic origin: 1999 to 2100. Washington, DC: U.S. Department of Commerce. Internet release NP-D1-A. <http://www.census.gov/population/www/projections/natdet-DIA.html>. 2000.
15. Freedman VA, Martin LG, Schoeni RF. Recent trends in disability and functioning among older adults in the United States: a systematic review. *JAMA* 2002;288(24):3137-46.
16. Alemayehu B, Warner KE. The lifetime distribution of health care costs. *Health Serv Res* 2004;39(3):627-42.
17. Yang Z, Norton EC, Stearns SC. Longevity and health care expenditures: the real reasons older people spend more. *J Gerontol B Psychol Sci Soc Sci* 2003;58(1):S2-10.
18. Hoover DR, Crystal S, Kumar R, et al. Medical expenditures during the last year of life: findings from the 1992-1996 Medicare current beneficiary survey. *Health Serv Res* 2002;37(6):1625-42.
19. Shugarman LR, Campbell DE, Bird CE, et al. Differences in Medicare expenditures during the last 3 years of life. *J Gen Intern Med* 2004;19(2):127-35.
20. Lubitz J, Cai L, Kramarow E, et al. Health, life expectancy, and health care spending among the elderly. *N Engl J Med* 2003;349(11):1048-55.
21. George LK. Research design in end-of-life research: state of science. *Gerontologist* 2002;42 Spec No 3:86-98.
22. Patrick DL, Curtis JR, Engelberg RA, et al. Measuring and improving the quality of dying and death. *Ann Intern Med* 2003;139(5 Pt 2):410-5.

23. Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? Opinions of bereaved family members. *J Am Geriatr Soc* 1997;45(11):1339-44.
24. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA* 1999;281(2):163-8. Comment in: *JAMA*. 1999 Apr 28;281(16):1488. PMID: 10227311.
25. Steihauser KE, Christakis NA, Clipp EC, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage* 2001;22(3):727-37.
26. Steihauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284(19):2476-82.
27. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291(1):88-93. Comment in: *JAMA*. 2004 Mar 24;291(12):1445-6; author reply 1446. PMID: 15039410.
28. Pierson CM, Curtis JR, Patrick DL. A good death: a qualitative study of patients with advanced AIDS. *AIDS Care* 2002;14(5):587-98.
29. Wenrich MD, Curtis JR, Ambrozy DA, et al. Dying patients' need for emotional support and personalized care from physicians: perspectives of patients with terminal illness, families, and health care providers. *J Pain Symptom Manage* 2003;25(3):236-46.
30. Teno J. TIME: Toolkit of Instruments to Measure End-of-life Care. available at URL: <http://www.chcr.brown.edu/pcoc/toolkit.htm>. Accessed 8/6/2004.
31. Teno JM, Clarridge B, Casey V, et al. Validation of Toolkit After-Death Bereaved Family Member Interview. *J Pain Symptom Manage* 2001;22(3):752-8.
32. National Cancer Policy Board. Improving palliative care for cancer: Summary and recommendations. Washington, DC: Institute of Medicine; 2001.
33. Institute of Medicine. Approaching death: Improving care at the end of life. Washington DC: National Academies Press; 1997.
34. Carr D, Goudas L, Lawrence D, et al. Management of cancer symptoms: pain, depression, and fatigue. Evidence report/technology assessment No. 61 (Prepared by the New England Medical Center Evidence-based Practice Center under Contract No 290-97-0019). AHRQ Publication No. 02-E032. Rockville, MD: Agency for Health Care Research and Quality. July 2002.
35. Institute of Medicine. 1st Annual Crossing the Quality Chasm Summit; In Press. Expected Sept 2004: 2004.
36. Cleeland CS, Gonin R, Hatfield AK, et al. Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med* 1994;330(9):592-6.
37. Morrison RS, Wallenstein S, Natale DK, et al. "We don't carry that"--failure of pharmacies in predominantly nonwhite neighborhoods to stock opioid analgesics. *N Engl J Med* 2000;342(14):1023-6.
38. Levenson JW, McCarthy EP, Lynn J, et al. The last six months of life for patients with congestive heart failure. *J Am Geriatr Soc* 2000;48(5 Suppl):S101-9.
39. Lynn J, Teno JM, Phillips RS, et al. Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Ann Intern Med* 1997;126(2):97-106. Comment in: *Ann Intern Med*. 1997 Aug 1;127(3):242-3. PMID: 9245235. Comment in: *Ann Intern Med*. 1997 Aug 1;127(3):242; author reply 243. PMID: 9245234. Comment in: *Ann Intern Med*. 1997 Aug 1;127(3):243. PMID: 9245236. Comment in: *Ann Intern Med*. 1.
40. Claessens MT, Lynn J, Zhong Z, et al. Dying with lung cancer or chronic obstructive pulmonary disease: insights from SUPPORT. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *J Am Geriatr Soc* 2000;48(5 Suppl):S146-53.
41. Gore JM, Brophy CJ, Greenstone MA. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax* 2000;55(12):1000-6. Comment in: *Thorax*. 2000 Dec;55(12):979-81. PMID: 11083879.
42. Lloyd-Williams M, Dennis M, Taylor F, et al. Is asking patients in palliative care, "are you depressed?" Appropriate? Prospective study. *BMJ* 2003;327(7411):372-3.

43. NIH State-of-the-Science Statement on symptom management in cancer: pain, depression, and fatigue. *NIH Consens State Sci Statements* 2002;19(4):1-29.
44. Hart DJ, Craig D, Compton SA, et al. A retrospective study of the behavioural and psychological symptoms of mid and late phase Alzheimer's disease. *Int J Geriatr Psychiatry* 2003;18(11):1037-42.
45. Bartels SJ, Horn SD, Smout RJ, et al. Agitation and depression in frail nursing home elderly patients with dementia: treatment characteristics and service use. *Am J Geriatr Psychiatry* 2003;11(2):231-8.
46. Wolfson C, Wolfson DB, Asgharian M, et al. A reevaluation of the duration of survival after the onset of dementia. *N Engl J Med* 2001;344(15):1111-6.
47. Yamamoto-Mitani N, Aneshensel CS, Levy-Storms L. Patterns of family visiting with institutionalized elders: the case of dementia. *J Gerontol B Psychol Sci Soc Sci* 2002;57(4):S234-46.
48. Tornatore JB, Grant LA. Burden among family caregivers of persons with Alzheimer's disease in nursing homes. *Gerontologist* 2002;42(4):497-506.
49. Schulz R, Belle SH, Czaja SJ, et al. Long-term care placement of dementia patients and caregiver health and well-being. *JAMA* 2004;292(8):961-7.
50. Emanuel EJ, Fairclough DL, Slutsman J, et al. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Annals of Internal Medicine* 2000;132(6):451-9.
51. Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *JAMA* 1994;272(23):1839-44.
52. Emanuel EJ, Fairclough DL, Slutsman J, et al. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Ann Intern Med* 2000;132(6):451-9.
53. Himmelstein DU, Thorne D, Warren E, et al. Medical Bankruptcy. *J Gen Intern Med* 2003;18(Suppl 1):221.
54. Covinsky KE, Landefeld CS, Teno J, et al. Is economic hardship on the families of the seriously ill associated with patient and surrogate care preferences? SUPPORT Investigators. *Arch Intern Med* 1996;156(15):1737-41.
55. Haggerty JL, Reid RJ, Freeman GK, et al. Continuity of care: a multidisciplinary review. *BMJ* 2003;327(7425):1219-21.
56. Boockvar K, Fishman E, Kyriacou CK, et al. Adverse events due to discontinuations in drug use and dose changes in patients transferred between acute and long-term care facilities. *Arch Intern Med* 2004;164(5):545-50.
57. Saliba D, Kington R, Buchanan J, et al. Appropriateness of the decision to transfer nursing facility residents to the hospital. *J Am Geriatr Soc* 2000;48(2):154-63.
58. Intrator O, Castle NG, Mor V. Facility characteristics associated with hospitalization of nursing home residents: results of a national study. *Med Care* 1999;37(3):228-37.
59. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291(1):88-93.
60. Teno JM, Lynn J. Putting advance-care planning into action. *J Clin Ethics* 1996;7(3):205-13.
61. Gillick MR. Advance care planning. *N Engl J Med* 2004;350(1):7-8.
62. Lunney JR, Lynn J, Foley DJ, et al. Patterns of functional decline at the end of life. *JAMA* 2003;289(18):2387-92.
63. Teno JM, Weitzen S, Fennell ML, et al. Dying trajectory in the last year of life: does cancer trajectory fit other diseases? *J Palliat Med* 2001;4(4):457-64.
64. Knaus WA, Harrell FE Jr, Lynn J, et al. The SUPPORT prognostic model. Objective estimates of survival for seriously ill hospitalized adults. Study to understand prognoses and preferences for outcomes and risks of treatments. *Ann Intern Med* 1995;122(3):191-203.
65. Covinsky KE, Eng C, Lui LY, et al. The last 2 years of life: functional trajectories of frail older people. *J Am Geriatr Soc* 2003;51(4):492-8.
66. Finlay IG, Higginson IJ, Goodwin DM, et al. Palliative care in hospital, hospice, at home: results from a systematic review. *Ann Oncol* 2002;13 Suppl 4:257-64.

67. Hearn J, Higginson IJ. Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliat Med* 1998;12(5):317-32.
68. Allard P, Maunsell E, Labbe J, et al. Educational interventions to improve cancer pain control: a systematic review. *J Palliat Med* 2001;4(2):191-203.
69. Devine EC. Meta-analysis of the effect of psychoeducational interventions on pain in adults with cancer. *Oncol Nurs Forum* 2003;30(1):75-89.
70. Jones J, Hunter D. Consensus methods for medical and health services research. *BMJ* 1995;311(7001):376-80.
71. Donabedian A. Explorations in Quality Assessment and Monitoring Volume I: The Definition of Quality and Approaches to its Assessment. Ann Arbor, MI: Health Administration Press. 1980.
72. Gysels M, Higginson IJ., eds. Improving supportive and palliative care for adults with cancer. Research Evidence Manual. London, National Institute of Clinical Excellence. 2003. URL: (http://www.nice.org.uk/pdf/SupportivePalliative_Research_Evidence_SecondDons.pdf)
73. Cook AM, Finlay IG, Edwards AG, et al. Efficiency of searching the grey literature in palliative care. *J Pain Symptom Manage* 2001;22(3):797-801.
74. Higginson IJ, Finlay IG, Goodwin DM, Cook AM, Edwards AGK, Hood K, et al. The role of palliative care teams: a systematic review of their effectiveness and cost-effectiveness. Report to Wales Office of Research and Development of the National Assembly of Wales. London, Department of Palliative Care and Policy. 2000.
75. Alderson P, Green S, Higgins JPT. Cochrane Reviewers' Handbook 4.2.2 [Updated December 2003]. In: The Cochrane Library, Issue 1, 2004. Chichester, UK: John Wiley & Sons, Ltd. 2004.
76. Sutton AJ, Abrams KR, Jones DR, Sheldon TA, Song F. Methods for Meta-Analysis in Medical Research. Wiley Series in Probability and Statistics. Chichester, UK: John Wiley & Sons. 2000.
77. Moher D, Cook DJ, Eastwood S, et al. Improving the quality of reports of meta-analyses of randomised controlled trials: the QUOROM statement. Quality of Reporting of Meta-analyses. *Lancet* 1999;354(9193):1896-900.
78. Stroup DF, Berlin JA, Morton SC, et al. Meta-analysis of observational studies in epidemiology: a proposal for reporting. Meta-analysis Of Observational Studies in Epidemiology (MOOSE) group. *JAMA* 2000;283(15):2008-12.
79. Colquitt J, Clegg A, Sidhu M, et al. Surgery for morbid obesity (Cochrane Review). *Cochrane Database Syst Rev* 2003;(2):CD003641.
80. Jadad AR, Moore RA, Carroll D, et al. Assessing the quality of reports of randomized clinical trials: is blinding necessary? *Control Clin Trials* 1996;17(1):1-12.
81. Rothman KJ, Greenland S. Modern Epidemiology. Philadelphia, PA: Lippincott-Raven Publishers. 1998.
82. Wilkinson EK, Salisbury C, Bosanquet N, et al. Patient and carer preference for, and satisfaction with, specialist models of palliative care: a systematic literature review. *Palliat Med* 1999;13(3):197-216.
83. Grande GE, Todd CJ, Barclay SI, et al. A randomized controlled trial of a hospital at home service for the terminally ill. *Palliat Med* 2000;14(5):375-85.
84. Ringdal GI, Jordhoy MS, Kaasa S. Family satisfaction with end-of-life care for cancer patients in a cluster randomized trial. *J Pain Symptom Manage* 2002;24(1):53-63.
85. Hanks GW, Robbins M, Sharp D, et al. The imPaCT study: a randomised controlled trial to evaluate a hospital palliative care team. *Br J Cancer* 2002;87(7):733-9.
86. Rabow MW, Dibble SL, Pantilat SZ, et al. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med* 2004;164(1):83-91.
87. Brumley RD, Enguidanos S, Cherin DA. Effectiveness of a home-based palliative care program for end-of-life. *J Palliat Med* 2003;6(5):715-24.

88. Weisbord SD, Carmody SS, Bruns FJ, et al. Symptom burden, quality of life, advance care planning and the potential value of palliative care in severely ill haemodialysis patients. *Nephrol Dial Transplant* 2003;18(7):1345-52. Comment in: *Nephrol Dial Transplant*. 2003 Dec;18(12):2688. PMID: 14605313.
89. Riegel B, Carlson B, Kopp Z, et al. Effect of a standardized nurse case-management telephone intervention on resource use in patients with chronic heart failure. *Arch Intern Med* 2002;162(6):705-12. Comment in: *Arch Intern Med*. 2002 Oct 14;162(18):2142-3; author reply 2143. PMID: 12374530.
90. Bruera E, Pituskin E, Calder K, et al. The addition of an audiocassette recording of a consultation to written recommendations for patients with advanced cancer: A randomized, controlled trial. *Cancer* 1999;86(11):2420-5.
91. Schneiderman LJ, Gilmer T, Teetzel HD, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. *JAMA* 2003;290(9):1166-72.
92. Molloy DW, Guyatt GH, Russo R, et al. Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. *JAMA* 2000;283(11):1437-44.
93. Guyatt GH, Mitchell A, Molloy DW, et al. Measuring patient and relative satisfaction with level or aggressiveness of care and involvement in care decisions in the context of life threatening illness. *J Clin Epidemiol* 1995;48(10):1215-24.
94. Bookbinder M, Coyle N, Kiss M, et al. Implementing national standards for cancer pain management: program model and evaluation. *J Pain Symptom Manage* 1996;12(6):334-47; discussion 331-3.
95. Pietersma P, Follett-Bick S, Wilkinson B, et al. A bedside food cart as an alternate food service for acute and palliative oncological patients. *Support Care Cancer* 2003;11(9):611-4.
96. Baker R, Wu AW, Teno JM et al. Family satisfaction with end-of-life care in seriously ill hospitalized adults. *J Am Geriatr Soc* 2000;48(5 Suppl):S61-9.
97. Heyland DK, Rocker GM, O'Callaghan CJ, et al. Dying in the ICU: perspectives of family members. *Chest* 2003;124(1):392-7. Comment in: *Chest*. 2003 Jul;124(1):11-2. PMID: 12853494.
98. Sulmasy DP, McIlvane JM. Patients' ratings of quality and satisfaction with care at the end of life. *Arch Intern Med* 2002;162(18):2098-104.
99. Steinhauer KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284(19):2476-82.
100. Zhukovsky DS, Gorowski E, Hausdorff J, et al. Unmet analgesic needs in cancer patients. *J Pain Symptom Manage* 1995;10(2):113-9.
101. Malacrida R, Bettelini CM, Degrade A, et al. Reasons for dissatisfaction: a survey of relatives of intensive care patients who died. *Crit Care Med* 1998;26(7):1187-93. Comment in: *Crit Care Med*. 1998 Jul;26(7):1150-1. PMID: 9671355. Comment in: *Crit Care Med*. 2000 Jan;28(1):289-90. PMID: 10667559.
102. Larsson BW, Larsson G, Carlson SR. Advanced home care: patients' opinions on quality compared with those of family members. *J Clin Nurs* 2004;13(2):226-33.
103. Kane RL, Homyak P, Bershadsky B, et al. Consumer responses to the Wisconsin Partnership Program for Elderly Persons: a variation on the PACE Model. *J Gerontol A Biol Sci Med Sci* 2002;57(4):M250-8.
104. Higginson IJ, Costantini M. Communication in end-of-life cancer care: a comparison of team assessments in three European countries. *J Clin Oncol* 2002;20(17):3674-82.
105. Tierney RM, Horton SM, Hannan TJ, et al. Relationships between symptom relief, quality of life, and satisfaction with hospice care. *Palliat Med* 1998;12(5):333-44.
106. Miceli PJ, Mylod DE. Satisfaction of families using end-of-life care: current successes and challenges in the hospice industry. *Am J Hosp Palliat Care* 2003;20(5):360-70.
107. Fakhoury W, McCarthy M, Addington-Hall J. Determinants of informal caregivers' satisfaction with services for dying cancer patients. *Soc Sci Med* 1996;42(5):721-31.
108. Fakhoury WK, McCarthy M, Addington-Hall J. The effects of the clinical characteristics of dying cancer patients on informal caregivers' satisfaction with palliative care. *Palliat Med* 1997;11(2):107-15.

109. Kristjanson LJ, Leis A, Koop PM, et al. Family members' care expectations, care perceptions, and satisfaction with advanced cancer care: results of a multi-site pilot study. *J Palliat Care* 1997;13(4):5-13.
110. Tolle SW, Tilden VP, Rosenfeld AG, et al. Family reports of barriers to optimal care of the dying. *Nurs Res* 2000;49 (6):310-7.
111. Dawson NJ. Need satisfaction in terminal care settings. *Soc Sci Med* 1991;32(1):83-7.
112. Jacoby A, Lecouturier J, Bradshaw C, et al. Feasibility of using postal questionnaires to examine carer satisfaction with palliative care: a methodological assessment. South Tyneside MAAG Palliative Care Study Group. *Palliat Med* 1999;13(4):285-98.
113. Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of End-of-Life Care in Dementia. *Alzheimer Dis Assoc Disord* 2001;15(4):194-200.
114. Tilden VP, Tolle SW, Drach LL, et al. Out-of-Hospital Death: Advance Care Planning, Decedent Symptoms, and Caregiver Burden. *J Am Geriatr Soc* 2004;52(4):532-9.
115. Fisher ES, Wennberg DE, Stukel TA, et al. The implications of regional variations in Medicare spending. Part 2: health outcomes and satisfaction with care. *Ann Intern Med* 2003;138(4):288-98. Comment in: *Ann Intern Med*. 2003 Feb 18;138(4):347-8. PMID: 12585834. Comment in: *Ann Intern Med*. 2003 Feb 18;138(4):348-9. PMID: 12585835. Comment in: *Ann Intern Med*. 2003 Feb 18;138(4):350-1. PMID: 12585836. Comment in: *Ann Intern Med*. 2004 Jan .
116. Cohen SR, Leis A. What determines the quality of life of terminally ill cancer patients from their own perspective? *J Palliat Care* 2002;18(1):48-58.
117. Conley VM, Burman ME. Informational needs of caregivers of terminal patients in a rural state. *Home Healthc Nurse* 1997;15(11):808-17.
118. Farber SJ, Egnew TR, Herman-Bertsch JL, et al. Issues in end-of-life care: patient, caregiver, and clinician perceptions. *J Palliat Med* 2003;6(1):19-31.
119. Hanson LC, Henderson M, Menon M. As individual as death itself: a focus group study of terminal care in nursing homes. *J Palliat Med* 2002;5(1):117-25.
120. Jacobs LG, Bonuck K, Burton W, et al. Hospital care at the end of life: an institutional assessment. *J Pain Symptom Manage* 2002;24(3):291-8.
121. Jarrett NJ, Payne SA, Wiles RA. Terminally ill patients' and lay-carers' perceptions and experiences of community-based services. *J Adv Nurs* 1999;29(2):476-83.
122. Jones RV, Hansford J, Fiske J . Death from cancer at home: the carers' perspective. *BMJ* 1993;306(6872):249-51. Comment in: *BMJ*. 1993 Mar 6;306(6878):648-9. PMID: 8461826. Comment in: *BMJ*. 1993 Mar 6;306(6878):649. PMID: 8461827.
123. Kirchhoff KT, Walker L, Hutton A, et al. The vortex: families' experiences with death in the intensive care unit. *Am J Crit Care* 2002;11(3):200-9.
124. McCain NL, Gramling LF. Living with dying: coping with HIV disease. *Issues Ment Health Nurs* 1992;13(3):271-84.
125. Murray SA, Boyd K, Kendall M, et al. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002;325(7370):929. Comment in: *BMJ*. 2002 Oct 26;325(7370):915-6. PMID: 12399323.
126. Proot IM, Abu-Saad HH, Crebolder HF, et al. Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scand J Caring Sci* 2003;17(2):113-21.
127. Rabow MW, Schanche K, Petersen J, et al. Patient perceptions of an outpatient palliative care intervention: "It had been on my mind before, but I did not know how to start talking about death...". *J Pain Symptom Manage* 2003;26(5):1010-5.
128. Rasmussen BH, Jansson L, Norberg A. Striving for becoming at-home in the midst of dying. *Am J Hosp Palliat Care* 2000;17(1):31-43.
129. Raynes NV, Leach JM, Rawlings B, et al. Using focus groups to seek the views of patients dying from cancer about the care they receive. *Health Expect* 2000;3(3):169-175.
130. Richardson J. Health promotion in palliative care: the patients' perception of therapeutic interaction with the palliative nurse in the primary care setting. *J Adv Nurs* 2002;40(4):432-40.

131. Ross LA. Elderly patients' perceptions of their spiritual needs and care: a pilot study. *J Adv Nurs* 1997;26(4):710-5.
132. Sinding C. Disarmed complaints: unpacking satisfaction with end-of-life care. *Soc Sci Med* 2003;57(8):1375-85.
133. Steinhauser KE, Clipp EC, McNeilly M, et al. In search of a good death: observations of patients, families, and providers. *Ann Intern Med* 2000;132(10):825-32.
134. Stiles MK. The shining stranger: application of the phenomenological method in the investigation of the nurse--family spiritual relationship. *Cancer Nurs* 1994;17(1):18-26.
135. Sunvisson H, Ekman SL. Environmental influences on the experiences of people with Parkinson's disease. *Nurs Inq* 2001;8(1):41-50.
136. Thomas J, Retsas A. Transacting self-preservation: a grounded theory of the spiritual dimensions of people with terminal cancer. *Int J Nurs Stud* 1999;36(3):191-201.
137. Vig EK, Davenport NA, Pearlman RA. Good deaths, bad deaths, and preferences for the end of life: a qualitative study of geriatric outpatients. *J Am Geriatr Soc* 2002;50(9):1541-8.
138. Vig EK, Pearlman RA. Quality of life while dying: a qualitative study of terminally ill older men. *J Am Geriatr Soc* 2003;51(11):1595-601.
139. Wenrich MD, Curtis JR, Ambrozy DA, et al. Dying patients' need for emotional support and personalized care from physicians: perspectives of patients with terminal illness, families, and health care providers. *J Pain Symptom Manage* 2003;25(3):236-46.
140. Wright K. Relationships with death: the terminally ill talk about dying. *J Marital Fam Ther* 2003;29(4):439-53.
141. Yedidia MJ, MacGregor B. Confronting the prospect of dying. reports of terminally ill patients. *J Pain Symptom Manage* 2001;22(4):807-19.
142. Braun KL, Zir A. Roles for the church in improving end-of-life care: perceptions of Christian clergy and laity. *Death Stud* 2001;25(8):685-704.
143. Chochinov HM, Hack T, McClement S, et al. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med* 2002;54(3):433-43.
144. Elliott J, Olver I. The discursive properties of "hope": a qualitative analysis of cancer patients' speech. *Qual Health Res* 2002;12(2):173-93.
145. McNamara B, Waddell C, Colvin M. The institutionalization of the good death. *Soc Sci Med* 1994;39(11):1501-8.
146. Raftery JP, Addington-Hall JM, MacDonald LD, et al. A randomized controlled trial of the cost-effectiveness of a district co-ordinating service for terminally ill cancer patients. *Palliat Med* 1996;10(2):151-61.
147. Hughes SL, Weaver FM, Giobbie-Hurder A, et al. Effectiveness of team-managed home-based primary care: a randomized multicenter trial. *JAMA* 2000;284(22):2877-85.
148. Cohen SR, Mount BM, Tomas JJ, et al. Existential well-being is an important determinant of quality of life. Evidence from the McGill Quality of Life Questionnaire. *Cancer* 1996;77(3):576-86.
149. Byock IR, Merriman MP. Measuring quality of life for patients with terminal illness: the Missoula-VITAS quality of life index. *Palliat Med* 1998;12(4):231-44.
150. Kyriaki M, Eleni T, Efi P, et al. The EORTC core quality of life questionnaire (QLQ-C30, version 3.0) in terminally ill cancer patients under palliative care: validity and reliability in a Hellenic sample. *Int J Cancer* 2001;94(1):135-9.
151. Herndon JE 2nd, Fleishman S, Kosty MP, et al. A longitudinal study of quality of life in advanced non-small cell lung cancer: Cancer and Leukemia Group B (CALGB) 8931. *Control Clin Trials* 1997;18(4):286-300. Comment in: *Control Clin Trials*. 1997 Aug;18(4):306-10. PMID: 9257069. Comment in: *Control Clin Trials*. 1997 Aug;18(4):311-7. PMID: 9257070.
152. Guo H, Fine PG, Mendoza TR, et al. A preliminary study of the utility of the brief hospice inventory. *J Pain Symptom Manage* 2001;22(2):637-48.
153. Llobera J, Esteva M, Benito E, et al. Quality of life for oncology patients during the terminal period. Validation of the HRCA-QL index. *Support Care Cancer* 2003;11(5):294-303.

154. Sterkenburg CA, King B, Woodward CA. A reliability and validity study of the McMaster Quality of Life Scale (MQLS) for a palliative population. *J Palliat Care* 1996;12(1):18-25.
155. Mystakidou K, Tsilika E, Kouloulis V, et al. The "Palliative Care Quality of Life Instrument (PQLI)" in terminal cancer patients. *Health Qual Life Outcomes* 2004;2(1):8.
156. Giorgi F, Cellerino R, Gramazio A, et al. Assessing quality of life in patients with cancer: a comparison of a visual-analogue and a categorical model. *Am J Clin Oncol* 1996;19(4):394-9.
157. Green CP, Porter CB, Bresnahan DR, et al. Development and evaluation of the Kansas City Cardiomyopathy Questionnaire: a new health status measure for heart failure. *J Am Coll Cardiol* 2000;35 (5):1245-55.
158. Higginson IJ, McCarthy M. Validity of the support team assessment schedule: do staffs' ratings reflect those made by patients or their families? *Palliat Med* 1993;7(3):219-28.
159. Carson MG, Fitch MI, Vachon ML. Measuring patient outcomes in palliative care: a reliability and validity study of the Support Team Assessment Schedule. *Palliat Med* 2000;14(1):25-36.
160. Steinhauer KE, Bosworth HB, Clipp EC, et al. Initial assessment of a new instrument to measure quality of life at the end of life. *J Palliat Med* 2002;5(6):829-41.
161. Salmon P, Manzi F, Valori RM. Measuring the meaning of life for patients with incurable cancer: the life evaluation questionnaire (LEQ). *Eur J Cancer* 1996;32A(5):755-60.
162. Kristjanson LJ. Validity and reliability testing of the FAMCARE Scale: measuring family satisfaction with advanced cancer care. *Social Science & Medicine* 1993;36(5):693-701.
163. Patrick DL, Engelberg RA, Curtis JR. Evaluating the quality of dying and death. *J Pain Symptom Manage* 2001;22(3):717-26.
164. Curtis JR, Patrick DL, Engelberg RA, et al. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Symptom Manage* 2002;24(1):17-31.
165. Hodde NM, Engelberg RA, Treece PD, et al. Factors associated with nurse assessment of the quality of dying and death in the intensive care unit. *Crit Care Med* 2004;32(8):1648-53.
166. Mularski R, Randall C, Osborne M, Engelberg R, Ganzini L. Agreement Among Family Members in Their Assessment of the Quality of Dying and Death. *Journal of pain and symptom management*. 2004;(In Press).
167. Sulmasy DP, McIlvane JM, Pasley PM, et al. A scale for measuring patient perceptions of the quality of end-of-life care and satisfaction with treatment: the reliability and validity of QUEST. *J Pain Symptom Manage* 2002;23(6):458-70.
168. Curtisa JR, Patrick DL, Caldwell E, et al. The quality of patient-doctor communication about end-of-life care: a study of patients with advanced AIDS and their primary care clinicians. *AIDS* 1999;13(9):1123-31.
169. Fried TR, Bradley EH, Towle VR. Assessment of patient preferences: integrating treatments and outcomes. *J Gerontol B Psychol Sci Soc Sci* 2002;57(6):S348-54.
170. Mystakidou K, Parpa E, Tsilika E, et al. The families evaluation on management, care and disclosure for terminal stage cancer patients. *BMC Palliat Care* 2002;1(1):3.
171. Gates MF, Lackey NR, White MR. Needs of hospice and clinic patients with cancer. *Cancer Pract* 1995;3(4):226-32. Comment in: *Cancer Pract*. 1995 Jul-Aug;3(4):201. PMID: 7620483.
172. Schwartz CE, Mazor K, Rogers J, et al. Validation of a new measure of concept of a good death. *J Palliat Med* 2003;6(4):575-84.
173. Emanuel LL, Alpert HR, Emanuel EE. Concise screening questions for clinical assessments of terminal care: the needs near the end-of-life care screening tool. *J Palliat Med* 2001;4(4):465-74.
174. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Palliative Care Core Audit Project Advisory Group*. *Qual Health Care* 1999;8(4):219-27.
175. Steel K, Ljunggren G, Topinkova E, et al. The RAI-PC: an assessment instrument for palliative care in all settings. *Am J Hosp Palliat Care* 2003;20(3):211-9.

176. Wilkie DJ, Huang HY, Reilly N, et al. Nociceptive and neuropathic pain in patients with lung cancer: a comparison of pain quality descriptors. *J Pain Symptom Manage* 2001;22(5):899-910.
177. Bruera E, Kuehn N, Miller MJ, et al. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991;7(2):6-9.
178. Lobchuk MM, Vorauer JD. Family caregiver perspective-taking and accuracy in estimating cancer patient symptom experiences. *Soc Sci Med* 2003;57(12):2379-84.
179. Tranmer JE, Heyland D, Dudgeon D, et al. Measuring the symptom experience of seriously ill cancer and noncancer hospitalized patients near the end of life with the memorial symptom assessment scale. *J Pain Symptom Manage* 2003;25(5):420-9.
180. Chang VT, Thaler HT, Polyak TA, et al. Quality of life and survival: the role of multidimensional symptom assessment. *Cancer* 1998;83(1):173-9.
181. Chow E, Wong R, Connolly R, et al. Prospective assessment of symptom palliation for patients attending a rapid response radiotherapy program. Feasibility of telephone follow-up. *J Pain Symptom Manage* 2001;22(2):649-56.
182. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. *Cancer* 2000;88(9):2164-71.
183. Ewing G, Todd C, Rogers M, et al. Validation of a symptom measure suitable for use among palliative care patients in the community: CAMPAS-R. *J Pain Symptom Manage* 2004;27(4):287-299.
184. Hoekstra J, Bindels PJ, van Duijn NP, et al. The symptom monitor. A diary for monitoring physical symptoms for cancer patients in palliative care: feasibility, reliability and compliance. *J Pain Symptom Manage* 2004;27(1):24-35.
185. Hollen PJ, Gralla RJ, Kris MG, et al. Measurement of quality of life in patients with lung cancer in multicenter trials of new therapies. Psychometric assessment of the Lung Cancer Symptom Scale. *Cancer* 1994;73(8):2087-98.
186. Hollen PJ, Gralla RJ, Kris MG, et al. Quality of life assessment in individuals with lung cancer: testing the Lung Cancer Symptom Scale (LCSS). *Eur J Cancer* 1993;29A Suppl 1:S51-8.
187. Hollen PJ, Gralla RJ, Kris MG, et al. Normative data and trends in quality of life from the Lung Cancer Symptom Scale (LCSS). *Support Care Cancer* 1999;7(3):140-8.
188. Sarna L, Brecht ML. Dimensions of symptom distress in women with advanced lung cancer: a factor analysis. *Heart Lung* 1997;26(1):23-30.
189. Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc* 2003;4(1):9-15. Comment in: *J Am Med Dir Assoc*. 2003 Jan-Feb;4(1):50-1. PMID: 12807599.
190. Chochinov HM, Wilson KG, Enns M, et al. "Are you depressed?" Screening for depression in the terminally ill. *Am J Psychiatry* 1997;154(5):674-6. Comment in: *Am J Psychiatry*. 1998 Jul;155(7):994-5. PMID: 9659876.
191. Morita T, Tsunoda J, Inoue S, et al. Communication Capacity Scale and Agitation Distress Scale to measure the severity of delirium in terminally ill cancer patients: a validation study. *Palliat Med* 2001;15(3):197-206.
192. Kurlowicz LH, Evans LK, Strumpf NE, et al. A psychometric evaluation of the Cornell Scale for Depression in Dementia in a frail, nursing home population. *Am J Geriatr Psychiatry* 2002;10(5):600-8.
193. Hopwood P, Howell A, Maguire P. Screening for psychiatric morbidity in patients with advanced breast cancer: validation of two self-report questionnaires. *British Journal of Cancer* 1991;64(2):353-6.
194. Kaasa T, Wessel J. The Edmonton Functional Assessment Tool: further development and validation for use in palliative care. *J Palliat Care* 2001;17(1):5-11.
195. Kaasa T, Wessel J, Darrah J, et al. Inter-rater reliability of formally trained and self-trained raters using the Edmonton Functional Assessment Tool. *Palliat Med* 2000;14(6):509-17.
196. Gerety MB, Mulrow CD, Tuley MR, et al. Development and validation of a physical performance instrument for the functionally impaired elderly: the Physical Disability Index (PDI). *J Gerontol* 1993;48(2):M33-8.
197. Gloth FM 3rd, Walston J, Meyer J, et al. Reliability and validity of the Frail Elderly Functional Assessment questionnaire. *Am J Phys Med Rehabil* 1995;74(1):45-53.

198. Koedoot N, Molenaar S, Oosterveld P, et al. The decisional conflict scale: further validation in two samples of Dutch oncology patients. *Patient Educ Couns* 2001;45(3):187-93.
199. Sherman AC, Simonton S, Adams DC, et al. Measuring religious faith in cancer patients: reliability and construct validity of the Santa Clara Strength of Religious Faith questionnaire. *Psycho-Oncology* 2001;10(5):436-43.
200. Dobratz MC. The Life Closure Scale: a measure of psychological adaptation in death and dying. *Hosp J* 1990;6(3):1-15.
201. Burnett P, Middleton W, Raphael B, et al. Measuring core bereavement phenomena. *Psychol Med* 1997;27(1):49-57.
202. Hogan NS, Greenfield DB, Schmidt LA. Development and validation of the Hogan Grief Reaction Checklist. *Death Stud* 2001;25(1):1-32.
203. Robinson LA, Nuamah IF, Lev E, et al. A prospective longitudinal investigation of spousal bereavement examining Parkes and Weiss' Bereavement Risk Index. *J Palliat Care* 1995;11(4):5-13.
204. Feldstein MA, Gemma PB. Oncology nurses and chronic compounded grief. *Cancer Nurs* 1995;18(3):228-36.
205. Travis SS, Bernard MA, McAuley WJ, et al. Development of the family caregiver medication administration hassles scale. *Gerontologist* 2003;43(3):360-8.
206. Kirschling JM, Tilden VP, Butterfield PG. Social support: the experience of hospice family caregivers. *Hosp J* 1990;6(2):75-93.
207. Kristjansson B, Breithaupt K, McDowell I. Development and validation of an indicator of support for community-residing older Canadians. *Int Psychogeriatr* 2001;13 Supp 1:125-35.
208. Hensch I, Gustafsson M. Pressure ulcers in palliative care: development of a hospice pressure ulcer risk assessment scale. *Int J Palliat Nurs* 2003;9(11):474-84.
209. Dooneief G, Marder K, Tang MX, et al. The Clinical Dementia Rating scale: community-based validation of "profound" and "terminal" stages. *Neurology* 1996;46(6):1746-9.
210. Fowell A, Finlay I, Johnstone R, et al. An integrated care pathway for the last two days of life: Wales-wide benchmarking in palliative care. *Int J Palliat Nurs* 2002;8(12):566-73. Comment in: *Int J Palliat Nurs*. 2003 Jan;9(1):39. PMID: 12560796.
211. Wilson D. Managing End of life pain and other symptoms through non-pharmacological means. *Integration of End of Life Care: A Health Canada Synthesis Research Project*. Edmonton, Alberta Canada: University of Alberta. draft in press.
212. Booth S, Anderson H, Swannick M, et al. The use of oxygen in the palliation of breathlessness. A report of the expert working group of the Scientific Committee of the Association of Palliative Medicine. *Respir Med* 2004;98(1):66-77.
213. Salman GF, Mosier MC, Beasley BW, et al. Rehabilitation for patients with chronic obstructive pulmonary disease: meta-analysis of randomized controlled trials. *J Gen Intern Med* 2003;18(3):213-21.
214. Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage* 2003;25(2):150-68.
215. Jennings AL, Davies AN, Higgins JP, et al. A systematic review of the use of opioids in the management of dyspnoea. *Thorax* 2002;57(11):939-44.
216. Pan CX, Morrison RS, Ness J, et al. Complementary and alternative medicine in the management of pain, dyspnea, and nausea and vomiting near the end of life. A systematic review. *J Pain Symptom Manage* 2000;20(5):374-87.
217. Finnema E, Droe RM, Ribbe M, et al. The effects of emotion-oriented approaches in the care for persons suffering from dementia: a review of the literature. *Int J Geriatr Psychiatry* 2000;15(2):141-61.
218. Opie J, Rosewarne R, O'Connor DW. The efficacy of psychosocial approaches to behaviour disorders in dementia: a systematic literature review. *Aust N Z J Psychiatry* 1999;33(6):789-99.
219. Forbes DA. Strategies for managing behavioural symptomatology associated with dementia of the Alzheimer type: a systematic overview. *Can J Nurs Res* 1998;30(2):67-86.

220. Goudas L, Carr DB, Bloch R et al. Management of Cancer Pain. (Prepared by the New England Medical Center Evidence-Based Practice Center under Contract No. 290-97-0019). Rockville, MD: Agency for Healthcare Research and Quality. 2001.
221. Jack B, Hillier V, Williams A, et al. Hospital based palliative care teams improve the symptoms of cancer patients. *Palliat Med* 2003;17(6):498-502.
222. Detmar SB, Muller MJ, Schornagel JH, et al. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *JAMA* 2002;288(23):3027-34. Comment in: *JAMA*. 2003 Apr 2;289(13):1636; author reply 1636-7. PMID: 12672729. Erratum in: *JAMA*. 2003 Feb 26;289(8):987.
223. Sarna L. Effectiveness of structured nursing assessment of symptom distress in advanced lung cancer. *Oncol Nurs Forum* 1998;25(6):1041-8.
224. Soden K, Vincent K, Craske S, et al. A randomized controlled trial of aromatherapy massage in a hospice setting. *Palliat Med* 2004;18(2):87-92.
225. Smith TJ, Staats PS, Deer T, et al. Randomized clinical trial of an implantable drug delivery system compared with comprehensive medical management for refractory cancer pain: impact on pain, drug-related toxicity, and survival. *Journal of Clinical Oncology* 2002;20(19):4040-9.
226. Mercadante S, Fulfaro F, Casuccio A. A randomised controlled study on the use of anti-inflammatory drugs in patients with cancer pain on morphine therapy: effects on dose-escalation and a pharmacoeconomic analysis. *Eur J Cancer* 2002;38(10):1358-63.
227. Simmons SF, Ferrell BA, Schnelle JF. Effects of a controlled exercise trial on pain in nursing home residents. *Clin J Pain* 2002;18(6):380-5.
228. Sittl R, Griessinger N, Likar R. Analgesic efficacy and tolerability of transdermal buprenorphine in patients with inadequately controlled chronic pain related to cancer and other disorders: a multicenter, randomized, double-blind, placebo-controlled trial. *Clinical Therapeutics* 2003;25(1):150-68.
229. Latimer EJ, Crabb MR, Roberts JG, et al. The Patient Care Travelling Record in palliative care: effectiveness and efficiency. *J Pain Symptom Manage* 1998;16(1):41-51.
230. Weiner P, Waizman J, Magadle R, et al. The effect of specific inspiratory muscle training on the sensation of dyspnea and exercise tolerance in patients with congestive heart failure. *Clin Cardiol* 1999;22(11):727-32.
231. Booth S, Kelly MJ, Cox NP, et al. Does oxygen help dyspnea in patients with cancer? *Am J Respir Crit Care Med* 1996;153(5):1515-8.
232. Mazzocato C, Buclin T, Rapin CH. The effects of morphine on dyspnea and ventilatory function in elderly patients with advanced cancer: a randomized double-blind controlled trial. *Ann Oncol* 1999;10(12):1511-4.
233. Jordhoy MS, Fayers P, Loge JH, et al. Quality of life in palliative cancer care: results from a cluster randomized trial. *J Clin Oncol* 2001;19(18):3884-94. Comment in: *J Clin Oncol*. 2002 Mar 15;20(6):1704-5. PMID: 11896122.
234. Bruera E, MacEachern T, Ripamonti C, et al. Subcutaneous morphine for dyspnea in cancer patients. *Ann Intern Med* 1993;119(9):906-7. Comment in: *Ann Intern Med*. 1994 Apr 15;120(8):692-3. PMID: 8192764.
235. Abernethy AP, Currow DC, Frith P, et al. Randomised, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnoea. *BMJ* 2003;327(7414):523-8.
236. Bruera E, Sweeney C, Willey J, et al. A randomized controlled trial of supplemental oxygen versus air in cancer patients with dyspnea. *Palliat Med* 2003;17(8):659-63.
237. Bruera E, de Stoutz N, Velasco-Leiva A, et al. Effects of oxygen on dyspnea in hypoxaemic terminal-cancer patients. *Lancet* 1993;342(8862):13-4.
238. Schofield P, Payne S. A pilot study into the use of a multisensory environment (Snoezelen) within a palliative day-care setting. *Int J Palliat Nurs* 2003;9(3):124-30. Erratum in: *Int J Palliat Nurs*. 2003 Apr;9(4):178.
239. Wilkinson S, Aldridge J, Salmon I, et al. An evaluation of aromatherapy massage in palliative care. *Palliat Med* 1999;13(5):409-17.
240. Stephenson NL, Weinrich SP, Tavakoli AS. The effects of foot reflexology on anxiety and pain in patients with breast and lung cancer. *Oncol Nurs Forum* 2000;27(1):67-72. Comment in: *Oncol Nurs Forum*. 2001 Apr;28(3):445-6. PMID: 11338752.

241. Gottlieb SS, Fisher ML, Freudenberger R, et al. Effects of exercise training on peak performance and quality of life in congestive heart failure patients. *J Card Fail* 1999;5(3):188-94.
242. Addington-Hall JM, MacDonald LD, Anderson HR, et al. Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. *BMJ* 1992;305(6865):1317-22.
243. Manfredi PL, Breuer B, Wallenstein S, et al. Opioid treatment for agitation in patients with advanced dementia. *International Journal of Geriatric Psychiatry* 2003;18(8):700-5.
244. Sultzer DL, Gray KF, Gunay I, et al. Does behavioral improvement with haloperidol or trazodone treatment depend on psychosis or mood symptoms in patients with dementia? *J Am Geriatr Soc* 2001;49(10):1294-300.
245. Rogers JC, Holm MB, Burgio LD, et al. Improving morning care routines of nursing home residents with dementia. *J Am Geriatr Soc* 1999;47(9):1049-57. Comment in: *J Am Geriatr Soc*. 1999 Sep;47(9):1151-2. PMID: 10484262.
246. Rovner BW, Steele CD, Shmueli Y, et al. A randomized trial of dementia care in nursing homes. *J Am Geriatr Soc* 1996;44(1):7-13. Comment in: *J Am Geriatr Soc*. 1996 Jan;44(1):91-2. PMID: 8537599. Comment in: *J Am Geriatr Soc*. 1996 Oct;44(10):1277-8. PMID: 8856018.
247. Goodwin DM, Higginson IJ, Myers K, et al. Effectiveness of palliative day care in improving pain, symptom control, and quality of life. *J Pain Symptom Manage* 2003;25(3):202-12. Comment in: *J Pain Symptom Manage*. 2003 Oct;26(4):886-7; author reply 888-9. PMID: 14527753.
248. Payne JL, Sheppard JM, Steinberg M, et al. Incidence, prevalence, and outcomes of depression in residents of a long-term care facility with dementia. *Int J Geriatr Psychiatry* 2002;17(3):247-53.
249. Goldberg RJ, Goldberg J. Risperidone for dementia-related disturbed behavior in nursing home residents: a clinical experience. *Int Psychogeriatr* 1997;9(1):65-8.
250. van der Steen JT, Ooms ME, van der Wal G, et al. Pneumonia: the demented patient's best friend? Discomfort after starting or withholding antibiotic treatment. *J Am Geriatr Soc* 2002;50(10):1681-8.
251. Friedman MM, Griffin JA. Relationship of physical symptoms and physical functioning to depression in patients with heart failure. *Heart Lung* 2001;30(2):98-104.
252. Fulop G, Strain JJ, Stettin G. Congestive heart failure and depression in older adults: clinical course and health services use 6 months after hospitalization. *Psychosomatics* 2003;44(5):367-73.
253. Rumsfeld JS, Havranek E, Masoudi FA, et al. Depressive symptoms are the strongest predictors of short-term declines in health status in patients with heart failure. *J Am Coll Cardiol* 2003;42(10):1811-7.
254. Jiang W, Alexander J, Christopher E, et al. Relationship of depression to increased risk of mortality and rehospitalization in patients with congestive heart failure. *Arch Intern Med* 2001;161(15):1849-56. Comment in: *Arch Intern Med*. 2002 Feb 11;162(3):362. PMID: 11822938. Comment in: *Arch Intern Med*. 2002 Feb 11;162(3):362-4. PMID: 11822939.
255. Acton GJ, Kang J. Interventions to reduce the burden of caregiving for an adult with dementia: a meta-analysis. *Res Nurs Health* 2001; 24(5):349-60.
256. Acton GJ, Winter MA. Interventions for family members caring for an elder with dementia. *Annu Rev Nurs Res* 2002;20 :149-79.
257. Yin T, Zhou Q, Bashford C. Burden on family members: caring for frail elderly: a meta-analysis of interventions. *Nurs Res* 2002;51(3):199-208.
258. Wilson D. Outcomes and Evaluation of end of life care. Integration of End of Life Care: A Health Canada Synthesis Research Project. Edmonton, Alberta Canada: University of Alberta. draft in press.
259. Wilson D. End of life case management. Integration of End of Life Care: A Health Canada Synthesis Research Project. Edmonton, Alberta Canada: University of Alberta. draft in press.
260. Wilson D. The needs of the families of dying persons. Integration of End of Life Care: A Health Canada Synthesis Research Project. Edmonton, Alberta Canada: University of Alberta. draft in press.
261. SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA* 1995;274(20):1591-8.

262. Ringdal GI, Ringdal K, Jordhoy MS, et al. Health-related quality of life (HRQOL) in family members of cancer victims: results from a longitudinal intervention study in Norway and Sweden. *Palliat Med* 2004;18(2):108-20.
263. Gitlin LN, Belle SH, Burgio LD, et al. Effect of multicomponent interventions on caregiver burden and depression: the REACH multisite initiative at 6-month follow-up. *Psychol Aging* 2003;18(3):361-74.
264. Burgio L, Stevens A, Guy D, et al. Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia. *Gerontologist* 2003;43(4):568-79.
265. Burns R, Nichols LO, Martindale-Adams J, et al. Primary care interventions for dementia caregivers: 2-year outcomes from the REACH study. *Gerontologist* 2003;43(4):547-55.
266. Eisdorfer C, Czaja SJ, Loewenstein DA, et al. The effect of a family therapy and technology-based intervention on caregiver depression. *Gerontologist* 2003;43(4):521-31.
267. Gitlin LN, Winter L, Corcoran M, et al. Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH Initiative. *Gerontologist* 2003;43(4):532-46.
268. Mahoney DF, Tarlow BJ, Jones RN. Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study. *Gerontologist* 2003;43(4):556-67.
269. Sorensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist* 2002;42(3):356-72.
270. Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *JAMA* 1994;272(23):1839-44.
271. Emanuel EJ, Fairclough DL, Slutsman J, et al. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *N Engl J Med* 1999;341(13):956-63.
272. Brazil K, Bedard M, Willison K, et al. Caregiving and its impact on families of the terminally ill. *Aging and Mental Health* 2003;7(5): 376-82.
273. Hodgson C, Higginson I, McDonnell M, et al. Family anxiety in advanced cancer: a multicentre prospective study in Ireland. *Br J Cancer* 1997;76(9):1211-4.
274. Collins C, Stommel M, Wang S, et al. Caregiving transitions: changes in depression among family caregivers of relatives with dementia. *Nurs Res* 1994;43(4):220-5.
275. Grant I, Adler KA, Patterson TL, et al. Health consequences of Alzheimer's caregiving transitions: effects of placement and bereavement. *Psychosom Med* 2002;64(3):477-86.
276. Hays JC, Kasl SV, Jacobs SC. The course of psychological distress following threatened and actual conjugal bereavement. *Psychol Med* 1994; 24(4):917-27.
277. Schulz R, Mendelsohn AB, Haley WE, et al. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *N Engl J Med* 2003;349(20):1936-42. Comment in: *N Engl J Med*. 2003 Nov 13;349(20):1891-2. PMID: 14614164. Comment in: *N Engl J Med*. 2004 Feb 12;350(7):733-4; author reply 733-4. PMID: 14960754.
278. Volicer L, Hurley AC, Blasi ZV. Characteristics of dementia end-of-life care across care settings. *Am J Hosp Palliat Care* 2003;20(3):191-200.
279. Martikainen P, Valkonen T. Do education and income buffer the effects of death of spouse on mortality? *Epidemiology* 1998;9(5):530-4.
280. Markowitz JS, Gutterman EM, Sadik K, et al. Health-related quality of life for caregivers of patients With Alzheimer disease. *Alzheimer Disease and Associated Disorders* 2003;17(4):209-214.
281. McCarthy M, Hall JA, Ley M. Communication and choice in dying from heart disease. *J R Soc Med* 1997;90(3):128-31.
282. Evangelista LS, Dracup K, Doering L, et al. Emotional well-being of heart failure patients and their caregivers. *J Card Fail* 2002;8(5):300-5.
283. Haggerty JL, Reid RJ, Freeman GK, et al. Continuity of care: a multidisciplinary review. *British Medical Journal* 2003;327:1219-1221.
284. Goodwin DM, Higginson IJ, Edwards AG, et al. An evaluation of systematic reviews of palliative care services. *J Palliat Care* 2002;18(2):77-83.

285. Smeenk FW, van Haastregt JC, de Witte LP, et al. Effectiveness of home care programmes for patients with incurable cancer on their quality of life and time spent in hospital: systematic review. *BMJ* 1998;316(7149):1939-44.
286. Wilson D. Continuity of end of life care. Integration of End of Life Care: A Health Canada Synthesis Research Project. Edmonton, Alberta Canada: University of Alberta. draft in press.
287. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA* 1995;274(20):1591-8. Comment in: *JAMA*. 1995 Nov 22-29;274(20):1634-6. PMID: 7474253. Comment in: *JAMA*. 1996 Apr 24;275(16):1227-8; author reply 1230-1. PMID: 8601945. Comment in: *JAMA*. 1996 Apr 24;275(16):1227; author reply 1230-1. PMID: 8601944. Comment in: *JAMA*. 1996.
288. Marbella AM, Desbiens NA, Mueller-Rizner N, et al. Surrogates' agreement with patients' resuscitation preferences: effect of age, relationship, and SUPPORT intervention. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Crit Care* 1998;13(3):140-5.
289. Schneiderman LJ, Gilmer T, Teetzel HD. Impact of ethics consultations in the intensive care setting: a randomized, controlled trial. *Critical Care Medicine* 2000;28(12):3920-4.
290. Ahrens T, Yancey V, Kollef M. Improving family communications at the end of life: implications for length of stay in the intensive care unit and resource use. *Am J Crit Care* 2003;12(4):317-23; discussion 324.
291. Grande GE, Todd CJ, Barclay SI, et al. Does hospital at home for palliative care facilitate death at home? Randomised controlled trial. *BMJ* 1999;319(7223):1472-5. Comment in: *BMJ*. 1999 Dec 4;319(7223):1447-8. PMID: 10582909.
292. DeCourtney CA, Jones K, Merriman MP, et al. Establishing a culturally sensitive palliative care program in rural Alaska Native American communities. *J Palliat Med* 2003;6(3):501-10.
293. Selwyn PA, Rivard M, Kappell D, et al. Palliative care for AIDS at a large urban teaching hospital: program description and preliminary outcomes. *J Palliat Med* 2003;6(3):461-74.
294. Stockelberg D, Lehtola P, Noren I. Palliative treatment at home for patients with haematological disorders. *Support Care Cancer* 1997;5(6): 506-8.
295. Melin AL, Bygren LO. Efficacy of the rehabilitation of elderly primary health care patients after short-stay hospital treatment. *Med Care* 1992;30(11):1004-15.
296. Mann WC, Ottenbacher KJ, Fraas L, et al. Effectiveness of assistive technology and environmental interventions in maintaining independence and reducing home care costs for the frail elderly. A randomized controlled trial. *Arch Fam Med* 1999;8(3):210-7. Comment in: *ACP J Club*. 1999 Nov-Dec;131(3):71.
297. McAlister FA, Lawson FM, Teo KK, et al. A systematic review of randomized trials of disease management programs in heart failure. *Am J Med* 2001;110(5):378-84.
298. Philbin EF. Comprehensive multidisciplinary programs for the management of patients with congestive heart failure. *J Gen Intern Med* 1999;14(2):130-5.
299. Phillips CO, Wright SM, Kern DE, et al. Comprehensive discharge planning with postdischarge support for older patients with congestive heart failure: a meta-analysis. *JAMA* 2004;291(11):1358-67.
300. McAlister FA, Stewart S, Ferrua S, et al. Multidisciplinary strategies for the management of heart failure patients at high risk for admission: a systematic review of randomized trials. *J Am Coll Cardiol* 2004;44(4):810-9.
301. Windham BG, Bennett RG, Gottlieb S. Care management interventions for older patients with congestive heart failure. *Am J Manag Care* 2003; 9(6):447-59; quiz 460-1.
302. Care of the dying: a Catholic perspective. Part III: Clinical context--good palliative care eases the dying process. *Catholic Health Association. Health Prog* 1993;74(4):22-6, 31.
303. Stewart S, Marley JE, Horowitz JD. Effects of a multidisciplinary, home-based intervention on unplanned readmissions and survival among patients with chronic congestive heart failure: a randomised controlled study. *Lancet* 1999;354(9184):1077-83.
304. Topp R, Tucker D, Weber C. Effect of a clinical case manager/clinical nurse specialist on patients hospitalized with congestive heart failure. *Nurs Case Manag* 1998;3(4):140-5; quiz 146-7, 182.

305. Roglieri JL, Futterman R, McDonough KL, et al. Disease management interventions to improve outcomes in congestive heart failure. *Am J Manag Care* 1997;3(12):1831-9.
306. Gorski LA, Johnson K. A disease management program for heart failure: collaboration between a home care agency and a care management organization. *Lippincotts Case Manag* 2003;8(6):265-73.
307. Jaarsma T, Halfens R, Huijter Abu-Saad H, et al. Effects of education and support on self-care and resource utilization in patients with heart failure. *Eur Heart J* 1999;20(9):673-82. Comment in: *Eur Heart J*. 1999 May;20(9):632-3. PMID: 10419340.
308. Heidenreich PA, Ruggiero CM, Massie BM. Effect of a home monitoring system on hospitalization and resource use for patients with heart failure. *Am Heart J* 1999;138(4 Pt 1):633-40. Comment in: *Am Heart J*. 1999 Oct;138(4 Pt 1):599-601. PMID: 10502199.
309. Lasater M. The effect of a nurse-managed CHF clinic on patient readmission and length of stay. *Home Healthc Nurse* 1996;14(5):351-6.
310. Jerant AF, Azari R, Nesbitt TS. Reducing the cost of frequent hospital admissions for congestive heart failure: a randomized trial of a home telecare intervention. *Med Care* 2001;39(11):1234-45.
311. Stewart S, Pearson S, Horowitz JD. Effects of a home-based intervention among patients with congestive heart failure discharged from acute hospital care. *Arch Intern Med* 1998;158(10):1067-72.
312. Goldberg LR, Piette JD, Walsh MN, et al. Randomized trial of a daily electronic home monitoring system in patients with advanced heart failure: the Weight Monitoring in Heart Failure (WHARF) trial. *Am Heart J* 2003; 146(4):705-12.
313. Philbin EF, Rocco TA, Lindenmuth NW, et al. The results of a randomized trial of a quality improvement intervention in the care of patients with heart failure. The MISCHF Study Investigators. *Am J Med* 2000;109(6):443-9. Comment in: *Am J Med*. 2000 Oct 15;109(6):501-3. PMID: 11042244.
314. Goodyer LI, Miskelly F, Milligan P. Does encouraging good compliance improve patients' clinical condition in heart failure? *Br J Clin Pract* 1995;49(4):173-6. Comment in: *Br J Clin Pract*. 1995 Jul-Aug;49(4):171. PMID: 7547152.
315. Phillips RS, Hamel MB, Teno JM, et al. Race, resource use, and survival in seriously ill hospitalized adults. The SUPPORT Investigators. *J Gen Intern Med* 1996;11(7):387-96.
316. Zweig SC, Kruse RL, Binder EF, et al. Effect of do-not-resuscitate orders on hospitalization of nursing home residents evaluated for lower respiratory infections. *J Am Geriatr Soc* 2004;52(1):51-8.
317. Intrator O, Zinn J, Mor V. Nursing home characteristics and potentially preventable hospitalizations of long-stay residents. *J Am Geriatr Soc* 2004;52(10):1730-6.
318. Tchen N, Bedard P, Yi QL, et al. Quality of life and understanding of disease status among cancer patients of different ethnic origin. *British Journal of Cancer* 2003;89(4):641-7.
319. Sulmasy DP, Sood JR. Factors associated with the time nurses spend at the bedsides of seriously ill patients with poor prognoses. *Med Care* 2003;41(4):458-66.
320. Hutt E, Ecord M, Eilertsen TB, et al. Precipitants of emergency room visits and acute hospitalization in short-stay Medicare nursing home residents. *J Am Geriatr Soc* 2002;50(2):223-9.
321. Fried TR, Mor V. Frailty and hospitalization of long-term stay nursing home residents. *J Am Geriatr Soc* 1997;45 (3):265-9. Comment in: *J Am Geriatr Soc*. 1997 Mar;45(3):378-9. PMID: 9063288.
322. Kane RL, Keckhafer G, Flood S, et al. The effect of Evercare on hospital use. *J Am Geriatr Soc* 2003;51(10):1427-34.
323. Townsend J, Frank AO, Fermont D, et al. Terminal cancer care and patients' preference for place of death: a prospective study. *BMJ* 1990;301(6749):415-7. Comment in: *BMJ*. 1993 Jun 26;306(6894):1754. PMID: 8343651.
324. Tang ST, Mccorkle R. Determinants of congruence between the preferred and actual place of death for terminally ill cancer patients. *J Palliat Care* 2003;19(4):230-7.
325. Chin MH, Goldman L. Correlates of early hospital readmission or death in patients with congestive heart failure. *Am J Cardiol* 1997;79(12):1640-4.

326. Stewart S, Horowitz JD. Detecting early clinical deterioration in chronic heart failure patients post-acute hospitalisation-a critical component of multidisciplinary, home-based intervention? *Eur J Heart Fail* 2002;4(3): 345-51.
327. Heller RF, Fisher JD, D'Este CA, et al. Death and readmission in the year after hospital admission with cardiovascular disease: the Hunter Area Heart and Stroke Register. *Med J Aust* 2000;172(6):261-5.
328. Burge F, Lawson B, Johnston G. Family physician continuity of care and emergency department use in end-of-life cancer care. *Med Care* 2003;41(8):992-1001.
329. Burge F, Lawson B, Johnston G, et al. Primary care continuity and location of death for those with cancer. *J Palliat Med* 2003;6(6):911-8.
330. Baggs JG. End-of-life care for older adults in ICUs. *Annu Rev Nurs Res* 2002 ;20:181-229.
331. Hanson LC, Tulskey JA, Danis M . Can clinical interventions change care at the end of life? *Ann Intern Med* 1997;126(5):381-8. Comment in: *Ann Intern Med*. 1997 Oct 1;127(7):574; author reply 574-5. PMID: 9313031. Comment in: *Ann Intern Med*. 1997 Oct 1;127(7):574; author reply 574-5. PMID: 9313030.
332. Higginson IJ, Finlay I, Goodwin DM, et al. Do hospital-based palliative teams improve care for patients or families at the end of life? *J Pain Symptom Manage* 2002;23(2):96-106.
333. Walsh RA, Girgis A, Sanson-Fisher RW. Breaking bad news. 2: What evidence is available to guide clinicians? *Behav Med* 1998;24(2):61-72.
334. Landry FJ, Kroenke K, Lucas C, et al. Increasing the use of advance directives in medical outpatients. *J Gen Intern Med* 1997;12(7):412-5.
335. Dexter PR, Wolinsky FD, Gramelspacher GP, et al. Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms. A randomized, controlled trial. *Ann Intern Med* 1998;128(2):102-10.
336. Smucker WD, Ditto PH, Moore KA, et al. Elderly outpatients respond favorably to a physician-initiated advance directive discussion. *J Am Board Fam Pract* 1993;6(5):473-82.
337. Schwartz CE, Wheeler HB, Hammes B, et al. Early intervention in planning end-of-life care with ambulatory geriatric patients: results of a pilot trial. *Arch Intern Med* 2002;162(14):1611-8.
338. Lilly CM, Sonna LA, Haley KJ, et al. Intensive communication: four-year follow-up from a clinical practice study. *Crit Care Med* 2003;31(5 Suppl):S394-9.
339. Dowdy MD, Robertson C, Bander JA. A study of proactive ethics consultation for critically and terminally ill patients with extended lengths of stay. *Critical Care Medicine* 1998;26(2):252-9.
340. Campbell ML, Guzman JA. Impact of a proactive approach to improve end-of-life care in a medical ICU. *Chest* 2003;123(1):266-71. Comment in: *Chest*. 2003 Jan;123(1):16-8. PMID: 12527596.
341. Holzapfel L, Demingon G, Piralla B, et al. A four-step protocol for limitation of treatment in terminal care. An observational study in 475 intensive care unit patients. *Intensive Care Med* 2002;28(9):1309-15. Comment in: *Intensive Care Med*. 2002 Sep;28(9):1197-9. PMID: 12400561.
342. Jack B, Hillier V, Williams A, et al. Hospital based palliative care teams improve the insight of cancer patients into their disease. *Palliat Med* 2004;18(1):46-52.
343. Butler JV, Pooviah PK, Cunningham D, et al. Improving decision-making and documentation relating to do not attempt resuscitation orders. *Resuscitation* 2003;57(2):139-44.
344. Monteleoni C, Clark E. Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: before and after study. *BMJ* 2004;329(7464):491-4.
345. Heffner JE, Fahy B, Hilling L, et al. Outcomes of advance directive education of pulmonary rehabilitation patients. *Am J Respir Crit Care Med* 1997;155(3):1055-9.
346. Anderson JP, Kaplan RM, Schneiderman LJ. Effects of offering advance directives on quality adjusted life expectancy and psychological well-being among ill adults. *J Clin Epidemiol* 1994;47(7):761-72.
347. Stuart B, D'Onofrio CN, Boatman S, et al. CHOICES: promoting early access to end-of-life care through home-based transition management. *J Palliat Med* 2003;6(4):671-83.

348. Ratner E, Norlander L, McSteen K. Death at home following a targeted advance-care planning process at home: the kitchen table discussion. *J Am Geriatr Soc* 2001;49(6):778-81. Comment in: *J Am Geriatr Soc*. 2001 Jun;49(6):833-4. PMID: 11454127.
349. Soskis CW. End-of-life decisions in the home care setting. *Soc Work Health Care* 1997;25(1-2):107-16.
350. Teno JM, Licks S, Lynn J, et al. Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Journal of the American Geriatrics Society* 1997;45(4):508-12.
351. Teno JM, Stevens M, Spornak S, et al. Role of written advance directives in decision making: insights from qualitative and quantitative data. *Journal of General Internal Medicine* 1998;13(7):439-46.
352. Golin CE, Wenger NS, Liu H, et al. A prospective study of patient-physician communication about resuscitation. *J Am Geriatr Soc* 2000;48(5 Suppl):S52-60.
353. Wenger NS, Phillips RS, Teno JM, et al. Physician understanding of patient resuscitation preferences: insights and clinical implications. *J Am Geriatr Soc* 2000;48(5 Suppl):S44-51.
354. Tierney WM, Dexter PR, Gramelspacher GP, et al. The effect of discussions about advance directives on patients' satisfaction with primary care. *J Gen Intern Med* 2001;16(1):32-40. Comment in: *J Gen Intern Med*. 2001 Jan;16(1):68-9. PMID: 11251753.
355. Rose JH, O'Toole EE, Dawson NV, et al. Generalists and oncologists show similar care practices and outcomes for hospitalized late-stage cancer patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks for Treatment. *Med Care* 2000;38(11):1103-18.
356. Curtis JR, Patrick DL, Caldwell ES, et al. Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. *Arch Intern Med* 2000;160(11):1690-6. Comment in: *Arch Intern Med*. 2000 Jun 12;160(11):1565-6. PMID: 10847247.
357. Junod Perron N, Morabia A, de Torrente A. Quality of life of Do-Not-Resuscitate (DNR) patients: how good are physicians in assessing DNR patients' quality of life? *Swiss Med Wkly* 2002;132(39-40):562-5.
358. Lockhart LK, Ditto PH, Danks JH, et al. The stability of older adults' judgments of fates better and worse than death. *Death Stud* 2001;25(4):299-317.
359. Detmar SB, Muller MJ, Schornagel JH, et al. Role of health-related quality of life in palliative chemotherapy treatment decisions. *J Clin Oncol* 2002;20(4):1056-62.
360. Butow PN, Maclean M, Dunn SM, et al. The dynamics of change: cancer patients' preferences for information, involvement and support. *Annals of Oncology* 1997;8(9):857-63.
361. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* 1998;279(21):1709-14. Comment in: *JAMA*. 1998 Jun 3;279(21):1746-8. PMID: 9624031. Comment in: *JAMA*. 1998 Oct 28;280(16):1403-4. PMID: 9800998. Comment in: *JAMA*. 1998 Oct 28;280(16):1403; author reply 1404. PMID: 9800997. Erratum in: *JAMA* 2000 Jan 12;283(2):203.
362. Phillips RS, Hamel MB, Teno JM, et al. Patient race and decisions to withhold or withdraw life-sustaining treatments for seriously ill hospitalized adults. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *American Journal of Medicine* 2000;108(1):14-9.
363. Wenger NS, Lynn J, Oye RK, et al. Withholding versus withdrawing life-sustaining treatment: patient factors and documentation associated with dialysis decisions. *Journal of the American Geriatrics Society* 2000;48(5 Suppl):S75-83.
364. Hakim RB, Teno JM, Harrell FE Jr, et al. Factors associated with do-not-resuscitate orders: patients' preferences, prognoses, and physicians' judgments. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Ann Intern Med* 1996;125(4):284-93.
365. Danis M, Southerland LI, Garrett JM, et al. A prospective study of advance directives for life-sustaining care. *N Engl J Med* 1991;324(13):882-8. Comment in: *N Engl J Med*. 1991 Oct 24;325(17):1254-6. PMID: 1922218.

366. McParland E, Likourezos A, Chichin E, et al. Stability of preferences regarding life-sustaining treatment: a two-year prospective study of nursing home residents. *Mt Sinai J Med* 2003;70(2):85-92.
367. Azoulay E, Chevret S, Leleu G, et al. Half the families of intensive care unit patients experience inadequate communication with physicians. *Critical Care Medicine* 2000;28(8):3044-9.
368. Hammes BJ, Rooney BL. Death and end-of-life planning in one midwestern community. *Arch Intern Med* 1998;158(4):383-90.
369. Shuster JL. ABCD Commends VA for End-of-Life Improvements. *ABCD Exchange* .
370. Tilden VP, Tolle SW, Drach LL, et al. Out-of-hospital death: advance care planning, decedent symptoms, and caregiver burden. *J Am Geriatr Soc* 2004;52(4):532-9.
371. Wilson D. Culture and end of life care. *Integration of End of Life Care: A Health Canada Synthesis Research Project*. Edmonton, Alberta Canada: University of Alberta. draft in press.
372. Wilson D. End of life care in acute care hospitals. *Integration of End of Life Care: A Health Canada Synthesis Research Project*. Edmonton, Alberta Canada: University of Alberta. draft in press.
373. Wilson D. End of life care in residential continuing-care facilities. *Integration of End of Life Care: A Health Canada Synthesis Research Project*. Edmonton, Alberta Canada: University of Alberta. draft in press.
374. Wilson D. The home as a place of end of life care. *Integration of End of Life Care: A Health Canada Synthesis Research Project*. Edmonton, Alberta Canada: University of Alberta. draft in press.
375. Farsides B, Dunlop RJ. Is there such a thing as a life not worth living? *BMJ* 2001;322(7300):1481-3.
376. McGown A, Braithwaite V. Stereotypes of emotional caregivers and their capacity to absorb information: the views of nurses, stroke carers and the general public. *J Adv Nurs* 1992;17(7):822-8.