

Notes on References

The following are selected references, divided by section, that provide the evidence base for the National Consensus Project Guidelines for Quality Palliative Care.¹ The references focus on well-designed, useful studies, both observational and experimental, as well as published consensus statements and expert opinions. Particularly in Domains 2 and 3 (the sections on physical and psychological distress), only a small portion of the relevant literature is provided.

All participants in the National Consensus Project (NCP) were invited to suggest key references. We also conducted a variety of literature searches in Medline and the Cochrane Collaboration, and reviewed many articles and textbooks, primarily in the fields of medicine and nursing. Where experimental evidence of good quality care exists, it is cited. Other references reflect the expert opinion of consensus efforts, professional organizations and experts in the field. This document does not represent an exhaustive review of the literature relevant to hospice and palliative care. For the Introduction and Domain 1: Structure and Processes of Care, which address fundamental features of palliative care, we provide thorough documentation, while in the sections on physical or psychological distress, key articles or recent summaries that complement the many excellent textbooks on palliation are cited under General References.

The National Hospice and Palliative Care Organization provided a “cross-walk” of the NCP guidelines with their Standards of Practice for Hospice Programs (2002). References to this document are listed in brackets.

A Note on the “State of the Science”

While many key concepts about end-of-life care were well articulated 40 years ago in the founding days of the hospice movement, an array of excellent studies can be cited in the past few decades during which palliative care has developed as a distinct discipline. Research that confirms, refines, extends and occasionally refutes hospice notions has blossomed, and the growth of the evidence base has been impressive in recent years. In selected areas, particularly in pain and symptom management, as well as in some aspects of psychological care and bereavement, well-designed experimental studies have begun to appear. Meanwhile, instruments appropriate for measuring palliative care outcomes, such as patient and family satisfaction, symptom distress, functional status, mood and quality of life, continue to improve.

¹ Note: For complete citations, go to the bibliography at www.nationalconsensusproject.org/guidelines.

The elements of palliative care have also become better defined and thus more subject to evaluation studies. For example, the use of artificial nutrition and hydration near the end of life is a practice generally shunned by hospice pioneers, and still often considered inappropriate for most dying patients. However, the utility of these interventions in selected patients is now recognized, but well-designed experimental studies are lacking. The randomized controlled trial has been difficult to carry out in the field of palliative care — being too intrusive and time consuming to be performed with very sick persons or with families under great stress. New measurement methodologies and study designs are needed.

Palliative care shares with other fields of medicine and nursing many well-recognized standards of care (e.g., continuity, communication, patient-centeredness) that have not been subjected to extensive, careful experimental verification. Some of the central tenets of the field — for example, interdisciplinary care, teamwork, patient-/family-centered decision-making, and an integrated, comprehensive approach to assessing and treating all forms of suffering — have never been validated in experimental studies. Demonstration projects and multi-center research will be necessary to test the utility of these care approaches in large patient populations.

The failings of the current health care system however, are well documented. The best documented and most consistent finding of numerous studies over the past few decades has been confirmation of the original observations of the founders of the hospice movement that inadequacies in symptom control, psychosocial and spiritual support (including bereavement care), shared decision-making, and attention to alternative sites of care fall short of common-sense standards for quality of care, leaving many observers (clinicians, patients, and family members) dissatisfied. A broad range of problems have been identified and extensively documented. These studies constitute the early descriptive phase of palliative care research. At the same time, hospice and palliative care have been shown to provide an alternative that consistently enhances patient and family satisfaction, often improves physical and emotional distress and regularly leads to cost-savings.

Many studies, mostly using survey methodology, offer a broad overview of this process, but except for studies of symptom management, there is a dearth of detailed examination of current practices and the impact of discrete interventions. For instance, late referrals to hospice programs in the United States have been decried for many years by proponents of palliative care. But the factors leading to this pattern, the impact of late referral on key outcomes and the effectiveness of various remedies have not been studied. More detailed qualitative and cross-cultural studies could be useful for understanding the forces that lead to this situation.

The science of palliative care is moving beyond its early, largely descriptive phase of development in which problems in end-of-life care were identified and solutions, although described, were not necessarily carefully tested.

References, by section

Introduction

- 1. Growth of hospice and palliative care programs in the United States:** (Robert Wood Johnson Foundation, Fund MM 2000; Billings JA, Pantilat S 2001; Pan CX, Morrison RS 2001; White KR, Cochran CE 2002; National Hospice and Palliative Care Organization 2003; Pantilat SZ, Billings JA 2003)
- 2. Palliative care is concurrent care, available from the time of diagnosis, not an alternative to “conventional” care:** (Ryndes T 1995; Portenoy RK 1998; MacDonald N 2002; Meyers FJ, Linder J 2003; Selwyn PA, Forstein M 2003)
- 3. Key recent reports promote the development of palliative care and hospice:** (Field MJ, Cassel CK 1997; Institute of Medicine 2001; American Association of Colleges of Nursing 2002; Field MJ, Behrman DE 2003; Jennings B, Ryndes T 2003)
- 4. Other important reports promote palliative care and hospice:** (Hastings Center 1987; American Nurses Association 1991a; American Nurses Association 1991b; American Nurses Association 1991c; American Nurses Association 1991d; American Nurses Association 1991a; Children’s Hospice International 1993; American Geriatrics Society Ethics Committee 1994; American Nurses Association 1994a; American Nurses Association 1994b; Jacox A., Carr D.B. 1994; American Pain Society Quality of Care Committee 1995; American Academy of Neurology Ethics and Humanities Subcommittee 1996; Council on Scientific Affairs AMA 1996; Hospice Nurses Association 1996; Higginson IJ, Sen-Gupta G 1997; Hospice and Palliative Nurses Association 1997; McSkimming SA, Super M 1997; National Council For Hospice And Specialist Palliative Care Services 1997; National Hospice Organization Standards and Accreditation Committee 1997; American Board of Internal Medicine Committee on Evaluation of Clinical Competence 1998; American Geriatrics Society Panel on Chronic Pain in Older Persons 1998; American Society of Clinical Oncology End of Life Task Force 1998; Ferrell BR, Virani R 1998; American Association of Critical-Care Nurses 1999; Emanuel LL, von Gunten CF 1999; Ferrell B.R., Grant M. 1999; Grossman SA, Benedetti C 1999; Hospice and Palliative Nurses Association 1999; National Comprehensive Cancer Network 1999; National Task Force on End-of-Life Care in Managed Care 1999; Oncology Nursing Society 1999; American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care 2000; American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health 2000; American Medical Directors Association 2000; Bednash G, Ferrell B 2000; Joint Commission on Accreditation of Healthcare Organizations 2000; National Hospice and Palliative Care Organization 2000; Brown ST, Blacker S 2001; Foley KM, Gelband H 2001; Hospice and Palliative Nurses Association 2001; National Advisory Committee on Palliative Care 2001; National Hospice and Palliative Care Organization 2001a; National Hospice and Palliative Care Organization 2001b; Roundtable O 2001; American Academy of Pediatrics and the American College of Emergency Physicians 2002; American College of Surgeons 2002; Ferris F. D., Balfour H. M. 2002; Hospice and Palliative Nurses Association 2002e; Hospice and Palliative Nurses Association 2002b; Hospice and Palliative Nurses Association 2002d; Hospice and Palliative Nurses Association 2002f; Hospice and Palliative Nurses Association 2002a; Hospice and Palliative Nurses Association 2002c; Hospice and Palliative Nurses Association, American Nurses Association 2002; Last Acts 2002; Medicare Payment Advisory Commission (MedPAC) 2002; Moon M, Boccutti C 2002; National Comprehensive Cancer Network 2002; National Hospice and Palliative Care Organization 2002; National Institute of Health Consensus Development Program 2002; American Medical Association Council on Ethics and Judicial Affairs 2003; American Nurses Association 2003; Fins JJ, Peres JR 2003; Hopper SS 2003; Hospice and Palliative Nurses Association 2003; National Comprehensive Cancer Network 2003b; National Comprehensive Cancer Network 2003a; National Hospice and Palliative Care Organization 2003; Hospice and Palliative Nurses Association 2004b; Hospice and Palliative Nurses Association 2004a; American Pain Society Task Force on Pain, Symptoms and End of Life Care undated; Smits HL, Furlotti M undated)
- 5. Definition of palliative care:** (Finlay IG, Jones RV 1995; Billings JA 1998; National Council For Hospice And Specialist Palliative Care Services 2002; World Health Organization 2002)
- 6. Modified from (World Health Organization 2002)**
- 7. A broad patient population is appropriate for palliative care:** (Field MJ, Cassel CK 1997; Mann SM, Welk TA 1997; Post LF, Dubler NN 1997; American Association of Colleges of Nursing 2002; Field MJ, Behrman DE 2003)
- 8. Patient-and family-centered care; the importance of eliciting and responding to patient and family values and goals:** (Kristjanson LJ 1986; Kristjanson LJ 1989; Goldberg R, Guadagnoli E 1990; Teno JM, Mor V 1991; Kristjanson LJ, Ashcroft T 1994; Murphy DJ, Burrows D 1994; 1995; Teno JM, Hakim RB 1995; Kristjanson LJ, Sloan JA 1996; Greisinger AJ, Lorimor RJ 1997; Kristjanson LJ, Leis A 1997; Kristjanson LJ, Nikolett S 1998; Krumholz HM, Phillips RS 1998; Singer PA, Martin DK 1999a; Singer PA, Martin DK 1999b; Teno JM 1999; Emanuel EJ, Fairclough DL 2000; Norton SA, Talerico KA 2000; Phillips RS,

Hamel MB 2000;Steinhauser KE, Christakis NA 2000;Steinhauser KE, Clipp EC 2000;Tolle SW, Tilden VP 2000;Andrews SC 2001;Bruera E, Sweeney C 2001;Price KJ,Kish SK 2001;Teno JM, Casey VA 2001;Contro N, Larson J 2002;Teno JM, Fisher ES 2002;American Academy of Pediatrics and the Institute for Family-Centered Care 2003;Carline JD, Curtis JR 2003;Teno JM, Clarridge BR 2004) {ARE 3, 3.1-3.3, 3.5, 3.6, 8, 14, 14.1, 14.2 HIFCCS 3; HIFCSIC 1,1.1-1.7, 5; HRCFSIC 1, 1.1-1.9, 2, 2.1-2.6, 3, 3.1, 5, 7, 7.1-7.4}. See also information-sharing (13), site of care (20, 26), advance care planning (34), and Domain 4: Social Aspects of Care, Domain 5: Spiritual, Religious and Existential Aspects of Care, and Domain 6: Cultural Aspects of Care.

9. **Professional assistance with decision-making:** (Murphy DJ, Burrows D 1994;Morrison RS, Zayas LH 1998;Braddock CH, 3rd., Edwards KA 1999;Baggs JG,Schmitt MH 2000;Borum ML, Lynn J 2000;Hopp FP,Duffy SA 2000;Foster LW,McLellan LJ 2002;Gattellari M, Voigt KJ 2002;Chao C, Studts JL 2003;Teno JM, Clarridge BR 2004)

10. **Comprehensive (integrated biopsychosocial/spiritual) care:** (Finlay IG,Jones RV 1995;Billings JA 1998;National Hospice and Palliative Care Organization 2000;Steinhauser KE, Clipp EC 2000;Tolle SW, Tilden VP 2000;Elliott J, Smith C 2001;Chochinov HM, Hack T 2002a;Lamberg L 2002;Patterson LB,Dorfman LT 2002;Ternestedt BM, Andershed B 2002)

11. **Interdisciplinary teamwork, interdisciplinary assessment, and team education:** (Given B,Simmons S 1977;Twycross RG 1990;Higginson IJ, Wade AM 1992;Shortell SM, Zimmerman JE 1994;Norsen L, Opladen J 1995;Council on Scientific Affairs AMA 1996;Billings JA,Block S 1997;Coyle N 1997;Field MJ,Cassel CK 1997;Higginson IJ,Hearn J 1997;O'Neill B,Fallon M 1997;Ross DD, O'Mara A 1997;American Board of Internal Medicine Committee on Evaluation of Clinical Competence 1998;Block S,Billings JA 1998;Ferrell BR, Virani R 1998;Ramirez A, Addington-Hall J 1998;Baggs JG, Schmitt MH 1999;Emanuel LL, von Gunten CF 1999;Ferrell B.R., Grant M. 1999;Lynn J,Harrold J 1999;Steel K, Ribbe M 1999;Abraham JL 2000;Benedetti C, Brock C 2000;Francke AL 2000;Freeborne N, Lynn J 2000;National Hospice and Palliative Care Organization 2000;Smeenk FW, de Witte LP 2000;Sommers LS, Marton KI 2000;Emanuel LL, Alpert HR 2001;Ferrell B,Coyle N 2001;Glass E, Cluxton D 2001;Krammer, Ringel SP 2001;Mularski RA, Bascom P 2001;Smith SA 2001;Zwarenstein M, Reeves S 2001;American Association of Colleges of Nursing 2002;Brown-Hellsten M, Hockenberry-Eaton M 2002;Higginson IJ, Finlay I 2002;Hospice and Palliative Nurses Association 2002d;Hospice and Palliative Nurses Association 2002f;Abraham JL 2003;De Conno F, Panzeri C 2003;Field MJ, Behrman DE 2003;Haggerty JL, Reid RJ 2003;Higginson IJ, Finlay IG 2003;Hospice and Palliative Nurses Association 2003;Matzo ML,Sherman DW 2003;Smith TJ, Coyne P 2003;Lickiss JN, Turner KS 2004) {IDT 1.1, 14, 14.1,14.2; HR 4, 4.1, 4.2, 4.4; CC 2.2;IT 1}

12. **Attention to relief of all forms of suffering:** (Cassell ES 1982;Cassell EJ 1991;Cassell EJ 1992;Cassell EJ 1999;National Hospice and Palliative Care Organization 2000;Thompson G,McClement S 2002)

13. **Communication skills: information-sharing and psychosocial support of patient and family:** (Buckman R 1992;Argent J, Faulkner A 1994;Murphy DJ, Burrows D 1994;Northouse LL, Dorris G 1995;1995;Diem SJ, Lantos JD 1996;Maguire P, Booth K 1996;Tulsky JA, Chesney MA 1996;Degner LF, Kristjanson LJ 1997;Quirt CF, Mackillop WJ 1997;Faulkner A 1998;Fischer GS, Tulsky JA 1998;Tulsky JA, Fischer GS 1998;Fischer GS, Arnold RM 2000;Hilden JM, Watterson J 2000;Larson DG,Tobin DR 2000;Leydon GM, Boulton M 2000;Morrison RS, Siu AL 2000;National Hospice and Palliative Care Organization 2000;Northouse LL, Mood D 2000;Roter DL, Larson S 2000;Steinhauser KE, Christakis NA 2000;Steinhauser KE, Clipp EC 2000;Breen CM, Abernethy AP 2001;Bucher JA, Loscalzo M 2001;Detmar SB, Muller MJ 2001;Faulkner A, Argent J 2001;Fins JJ,Solomon MZ 2001;Glajchen M,Zuckerman C 2001;Perrin KO 2001;Scott JT, Entwistle VA 2001;Clever SL,Tulsky JA 2002;Emanuel EJ, Ash A 2002;Kolarik RC, Arnold RM 2002;Rauch P,Arnold R 2002;Rauch PK, Muriel AC 2002;Tattersall MH, Gattellari M 2002;Back AL, Arnold RM 2003;Byock I,Miles SH 2003;Field MJ, Behrman DE 2003;Scott JT, Harmsen M 2003;Seymour J 2003;Fallowfield L 2004;Jeffrey D 2004;Maguire P,Pitceathly C 2004) {CCS 3.3, 6, 11,12.3, 13, 13.1, 13.2, 14, 14.1, 14.2; IDT 4.1, 5.1; HR 7.2}

14. **Palliative care team members have professional-level expertise in care of the dying and bereaved, and are appropriately credentialed:** (Twycross RG 1990;Council on Scientific Affairs AMA 1996;Frager G 1996;Billings JA,Block S 1997;Frager G 1997;O'Neill B,Fallon M 1997;Ross DD, O'Mara A 1997;American Board of Internal Medicine Committee on Evaluation of Clinical Competence 1998;Block S,Billings JA 1998;Ferrell BR, Virani R 1998;Ramirez A, Addington-Hall J 1998;Emanuel LL, von Gunten CF 1999;Ferrell BR, Grant M. 1999;Lynn J,Harrold J 1999;Steel K, Ribbe M 1999;Abraham JL 2000;American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care 2000;Benedetti C, Brock C 2000;Freeborne N, Lynn J 2000;National Hospice and Palliative Care Organization 2000;von Gunten CF, Ferris FD 2000;2001;Ferrell B,Coyle N 2001;Hospice and Palliative Nurses Association 2001;Krammer, Ringel SP 2001;Mularski RA, Bascom P 2001;Smith SA 2001;Wilkie DJ 2001;Wilkie DJ, Brown MA 2001;American Association of Colleges of Nursing 2002;Billings JA, Block SD 2002;Hospice and Palliative Nurses Association 2002d;Hospice and Palliative Nurses Association 2002f;Hospice and Palliative Nurses Association 2002a;Hospice and Palliative Nurses Association 2002c;Hospice and Palliative Nurses Association,American Nurses Association 2002;Meier DE 2002;Abraham JL 2003;Hospice and Palliative Nurses Association 2003;Matzo ML,Sherman DW 2003) {IDT 1.1; 15;HR 1, 1.3, 4, 4.1, 4.2, 4.4}

15. **Continuity of care across settings:** (Field MJ,Cassel CK 1997;Higginson I 1999;Morrison RS, Siu AL 2000;Blackford J,Street A 2001;Ferris FD, Balfour HM 2002;Friedman BT, Harwood MK 2002;Moore S, Corner J 2002;Bliss J,While A 2003;Burge F, Lawson B 2003;Field MJ, Behrman DE 2003;Haggerty JL, Reid RJ 2003;Jennings B, Ryndes T 2003;Moore C, Wisnivesky J 2003;Nelson KA,Walsh D 2003;Ryndes T,Emanuel L 2003;Twaddle ML, Sheehan M 2003)

16. **Equitable access to services:** (National Hospice and Palliative Care Organization 2000;Smeenk FW, de Witte LP 2000;Meier D. E. 2002;Jennings B, Ryndes T 2003)

16a. **Addressing regulatory barriers and concerns:** (Field MJ, Cassel CK 1997; Meisel A, Snyder L 2000; Drug Enforcement Administration, Last Acts 2001; Joranson DE, Gilson AM 2003; Pain and Policy Studies Group 2003; Savage SR, Joranson DE 2003)

17. **Quality improvement and quality assurance:** (McCarthy M,Higginson I 1991;Higginson I 1993;McWhinney IR, Bass MJ 1994;American Pain Society Quality of Care Committee 1995;Coynne PJ 1995;Bruera E 1996b;Campbell ML 1996;Hearn J,Higginson IJ 1997;Lynn J 1997;National Hospice and Palliative Care Organization 1997;National Hospice Organization Standards and Accreditation Committee 1997;Rudberg MA, Teno JM 1997;Scanlon C 1997;Teno JM, Landrum K 1997;American Board of Internal Medicine Committee on Evaluation of Clinical Competence 1998;Donaldson MS,Field MJ 1998;Robbins M 1998;United Hospital Fund 1998;Du Pen SL, Du Pen AR 1999;Teno JM,Coppola KM 1999;Lynn J 2000;Morrison RS, Siu AL 2000;Reese D, Raymer M 2000;Rosenfeld K,Wenger NS 2000;Teno J 2000;Ellershaw J, Smith C 2001;Hermann CP 2001;Institute of Medicine Committee on Quality Health Care in America, Institute of Medicine, 2001;Kizer KW 2001b;Kizer KW 2001a;Teno JM, Clarridge B 2001;Teno JM, Field MJ 2001;Epstein RM,Hundert EM 2002;Hanks GW, Robbins M 2002;Last Acts 2002;Lynn J, Nolan K 2002;National Quality Forum 2002;Shaughnessy PW, Hittle DF 2002;Steinhauser KE, Bosworth HB 2002;Steinhauser KE, Clipp EC 2002;Thompson G,McClement S 2002;Aspinal F, Addington-Hall J 2003;McGlynn EA, Cassel CK 2003;National Quality Forum 2003) {PI 1.1, 2, 2.1-2.3, 3.2, 4, 4.1, 4.3, 4.4, 5.2, 5.3, 6, 6.1,6.2}

18. **The need for pediatric services:** (Kazak AE, Penati B 1996;American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care 2000;Children's International Project on Palliative/Hospice Services (ChIPPS) 2000;Hilden JM, Watterson J 2000;McCallum DE, Byrne P 2000;Sahler OJ, Frager G 2000;Wolfe J 2000;Wolfe J, Grier HE 2000;Children's International Project on Palliative/Hospice Services (ChIPPS) 2001;Feudtner C, Hays RM 2001;Contro N, Larson J 2002;Davies B, Brenner P 2002;Rauch P,Arnold R 2002;Rauch PK, Muriel AC 2002;Davies B, Collins JB 2003;Field MJ, Behrman DE 2003;Higginson IJ,Thompson M 2003;Solomon MZ, Browning D 2003)

19. **Programs provide a range of services in a variety of settings:** (Munley A, Powers CS 1982;Haines A,Booroff A 1986;Higginson IJ, Wade AM 1992;Mercadante S, Genovese G 1992;Dudgeon DJ,Kristjansson L 1995;Ferrell BA 1995;O'Brien LA, Grisso JA 1995;Castle NG, Mor V 1997;Meier DE, Morrison RS 1997;Weissman DE 1997;Bernabei R, Gambassi G 1998;Bradley EH, Peiris V 1998;Dunlop RJ,Hockley JM 1998;Ferrell BR, Virani R 1998;Smeenk FW, van Haastregt JC 1998;Petrisek AC,Mor V 1999;Steel K, Ribbe M 1999;Tolle SW, Rosenfeld AG 1999;Center to Advance Palliative Care 2000;Roush CV,Cox JE 2000;Zerzan J, Stearns S 2000;Billings JA, Ferris FD 2001;Billings JA,Pantilat S 2001;Cain JM 2001;DeSilva DL, Dillon JE 2001;Miller SC, Gozalo P 2001;Miller SC,Mor V 2001;Pan CX, Morrison RS 2001;Ratner E, Norlander L 2001;Teno JM, Weitzen S 2001;Ferrell BR,Borneman T 2002;Finlay IG, Higginson IJ 2002;Hanks GW, Robbins M 2002;Happ MB, Capezuti E 2002;Homs J, Walsh D 2002;Meier D.E. 2002;Miller SC, Mor V 2002;Miller SC,Mor VN 2002;Pantilat SZ 2002;Reynolds K, Henderson M 2002;Santa-Emma PH, Roach R 2002;von Gunten CF 2002b;Brumley RD, Enguidanos S 2003;Higginson IJ, Finlay IG 2003;Kayser-Jones J, Schell E 2003;Keay TJ, Alexander C 2003;Lilly CM, Sonna LA 2003;Meier DE, Thar W 2003;Miller SC, Mor V 2003;Murkofsky RL, Phillips RS 2003;Pantilat SZ,Billings JA 2003;Zimmerman S, Sloane PD 2003;Teno JM, Clarridge BR 2004)

20. **The need for home services recognizing patient and family preferences:** (Koenig BA,Gates-Williams J 1995;American Society of Clinical Oncology End of Life Task Force 1998;Morrison RS, Zayas LH 1998;Smeenk FW, van Haastregt JC 1998;Wennberg J,Cooper M 1998;Loudon RF, Anderson PM 1999;American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care 2000;Emanuel EJ, Fairclough DL 2000;Hopp FP,Duffy SA 2000;Keovilay L, Rasbridge L 2000;Waters CM 2000;Middlewood S, Gardner G 2001;Ratner E, Norlander L 2001;Billings JA, Block SD 2002;Bruera E, Russell N 2002;Bruera E, Sweeney C 2003;Teno LM 2003) {ARE 3.5; CCS 10.2, 13.2, 14; CC 3.1-3.4}

21. **Attention to caregiver burden and support:** (Tolle SW,Girard DE 1983;Tolle SW, Elliot DL 1984;Tolle SW, Bascom PB 1986;Labrecque MS, Blanchard CG 1991;Higginson I, Priest P 1994;Kristjansson LJ,Ashcroft T 1994;Kristjansson LJ, Atwood J 1995;1995;Kristjansson LJ, Sloan JA 1996;Hanson LC, Danis M 1997;Kristjansson LJ, Leis A 1997;Lynn J, Teno JM 1997;Morrison RS, Ahronheim JC 1998;Bern-Klug M, Ekerdt DJ 1999;Singer PA, Martin DK 1999a;Yates P,Stetz KM 1999;Baker R, Wu AW 2000;Early BP, Smith ED 2000;Emanuel EJ, Fairclough DL 2000;Levine C 2000;Steinhauser KE, Christakis NA 2000;Tolle SW, Tilden VP 2000;Andrews SC 2001;Goetschius SK 2001;Hickman SE, Tilden VP 2001;Perrin KO 2001;Teno JM, Clarridge B 2001;Foster LW,McLellan LJ 2002;Main J 2002;Patterson LB,Dorfman LT 2002;Brazil K, Bedard M 2003;Brodady H, Green A 2003;Christakis NA,Iwashyna TJ 2003;Dawson S,Kristjansson LJ 2003;Deeken JF, Taylor KL 2003;Doukas DJ,Hardwig J 2003;Harding R,Higginson IJ 2003;Hecht MJ, Graesel E 2003;Markowitz JS, Gutterman EM 2003;Seymour J 2003;Stuart B, D'Onofrio CN 2003;Williams PD, Williams AR 2003;Rabow MW, Hauser JM 2004) {CCS 3.3, 10, 10.1-10.3, 11, 11.1, 11.3, 13, 13.1, 13.2, 14, 14.1, 14.2; IDT 4.1, 5.1; HR 7.2}

22. **Palliative care improves patient satisfaction and other outcomes:** (Zimmer JG, Groth-Juncker A 1984;Zimmer JG, Groth-Juncker A 1985;Mor V 1987;Mor V, Greer DS 1988;Campbell ML, Frank RR 1997;Hanson LC, Tulskey JA 1997;Smeenk FW, van Haastregt JC 1998;Bosanquet N,Salisbury C 1999;Bruera E, Neumann CM 1999;Grande GE, Todd CJ 2000;Schneiderman LJ, Gilmer T 2000;Cohen SR, Boston P 2001;Jack B, Oldham J 2002;Campbell ML,Guzman JA 2003;Jack B, Hillier V 2003;Jack B, Oldham J 2003;Rabow MW, Petersen J 2003;Rabow MW, Schanche K 2003;Schneiderman LJ, Gilmer T 2003;Christakis NA, Iwashyna TJ 2003;Teno JM, Clarridge BR 2004)

23. **Palliative care has fiscal benefits:** (Lubitz J, Prihoda R 1984; Zimmer JG, Groth-Juncker A 1984; Zimmer JG, Groth-Juncker A 1985; Mor V 1987; Riley G, Lubitz J 1987; Mor V, Greer DS 1988; McMillan A, Mentnech RM 1990; Lubitz JD, Riley GF 1993; Riley GF, Potosky AL 1995; Raftery JP, Addington-Hall JM 1996; Bruera E, Neumann CM 1999; Hogan C, Lunney J 2001; Serra-Prat M, Gallo P 2001; Beresford J, Byock I 2002; Moore S, Corner J 2002; Cintron A, Hamel MB 2003; Costantini M, Higginson IJ 2003; McCarthy EP, Burns RB 2003a; McCarthy EP, Burns RB 2003b; Smith TJ, Coyne P 2003; Cost Accounting Peer Workgroup Promoting Excellence in End-of-Life Care 2004)

24. **Palliative care improves hospice utilization:** (Mor V 1987; Mor V, Greer DS 1988; Schapiro R, Byock I 2003)

25. **Aging America:** (Burman L, Penner R 1998)

26. **Where people die and where they want to die:** (Teno JM 2003; Hansen LC, Henderson M 2002; Wennberg J, Copper M 1998; Kemper P, Murtaugh CM 1991; Bruera E, Russell N 2002; Furst CJ, Doyle D 2004; Ratner E, Norlander L 2001; Jordhoy MS, Foyers P 2000; Haines A, Booroff A 1986; Teno JM, Clarridge BR 2004; Weitzen S, Teno JM 2003) {CCS 6, 13; CC 3, 3.1, 3.2}

27. **Problems of burdensome technologies:** (Teno JM, Fisher ES 2002)

28. **Need for education about palliative care for all health professionals, especially in hospitals:** (Sanson-Fisher R, Maguire P 1980; Sanson-Fisher R, Fairbairn S 1981; Maguire P, Fairbairn S 1986b; Maguire P, Fairbairn S 1986a; Arnold RM, Forrow L 1988; Maguire P, Faulkner A 1988; Weissman DE 1991; Billings JA 1993; Bird J, Hall A 1993; Covinsky KE, Goldman L 1994; 1995; Tulsy JA, Chesney MA 1995; Billings JA, Block S 1997; Bruera E, Selmsler P 1997; Campbell ML, Frank RR 1997; Field MJ, Cassel CK 1997; Manias E, Kristjanson L 1997; Ross DD, O'Mara A 1997; Seely JF, Scott JF 1997; Block S, Billings JA 1998; Ferrell BR, Virani R 1998; Oneschuk D, Bruera E 1998; Danis M, Federman D 1999; Emanuel LL, von Gunten CF 1999; Ersek M, Kraybill BM 1999; Ferrell B, Virani R 1999a; Ferrell B, Virani R 1999b; Ferrell B, Grant M. 1999; Ferrell BR, Juarez G 1999; Linder JF, Blais J 1999; Steel K, Ribbe M 1999; Weissman DE, Block SD 1999; Ferrell B, Virani R 2000b; Ferrell BR, Virani R 2000; Fins JJ, Nilson EG 2000; Lynn J, Schuster JL 2000; Meekin SA, Klein JE 2000; Meisel A, Snyder L 2000; Oneschuk D, Hanson J 2000b; Sahler OJ, Frager G 2000; Tolle SW, Tilden VP 2000; Wenger NS, Phillips RS 2000; Faulkner A, Argent J 2001; Jubelirer SJ, Welch C 2001; Mularski RA, Bascom P 2001; Murphy-Ende K 2001; Novak B, Kolcaba K 2001; Ross DD, Fraser HC 2001; Weissman DE, Mullan P 2001; American Association of Colleges of Nursing 2002; Aronson SG, Kirby RW 2002; Billings JA, Block SD 2002; Ferrell BR, Borneman T 2002; Maguire P, Pitceathly C 2002; Mullan PB, Weissman DE 2002; Spiegel MJ, Meier DE 2002; Weissman DE, Block SD 2002; Weissman DE, Mullan PB 2002; Back AL, Arnold RM 2003; Keay TJ, Alexander C 2003; Razavi D, Merckaert I 2003; Sullivan AM, Lakoma MD 2003)

29. **Hospice improves nursing home outcomes:** (Baer WM, Hanson LC 2000; Gage B, Miller S 2000; Miller SC, Gozalo P 2000)

30. **Professional organizations, programs and studies supporting improved end-of-life care in nursing homes:** (Castle NG, Mor V 1997; Bernabei R, Gambassi G 1998; Bradley EH, Peiris V 1998; Petrisek AC, Mor V 1999; Steel K, Ribbe M 1999; American Medical Directors Association 2000; Hanson LC, Henderson M 2000; Miller S, 2000; Zerzan J, Stearns S 2000; DeSilva DL, Dillon JE 2001; Miller SC, Mor V 2001; Hanson LC, Henderson M 2002; Miller SC, Mor V 2002; Reynolds K, Henderson M 2002; Keay TJ, Alexander C 2003; Meador R, Hegeman C 2003; Miller SC, Mor V 2003)

31. **Palliative care guidelines from other health care systems:** See also Appendix 1 (Palliative Care Australia 1998; Palliative Care Australia 1999; Freeborne N, Lynn J 2000; Palliative Care Australia 2000; National Advisory Committee on Palliative Care 2001; New Zealand Ministry of Health 2001; Ferris F. D., Balfour H.M. 2002; Association for Palliative Medicine of Great Britain and Ireland)

32. **Evidence-based guidelines and improvement of palliative care practice over time:** (Higginson I, Wade A 1990; Jacox A., Carr D.B. 1994; Higginson IJ, Hearn J 1996; Kuebler KK, Dahlin C 1996; Gance LG, Osler T 1998; Grossman SA, Benedetti C 1999; National Comprehensive Cancer Network 1999; National Comprehensive Cancer Network 2003b)

Domain 1: Structure and Processes of Care

33. **Assessment requires complete review of history, physical examination, laboratory studies, records, etc.:** (Bruera E 1996a; Dunn GP 2001) {CCS 1.2, 1.3, 3, 6; IDT 3.1}

34. **Advance care planning:** (American Nurses Association 1991c; American Nurses Association 1991d; Lynn J, Teno JM 1993; Teno J, Lynn J 1993; Teno JM, Sabatino C 1993; Cherny NI, Portenoy RK 1994; Teno JM, Lynn J 1994; Teno JM, Nelson HL 1994; Tulsy JA, Chesney MA 1995; Covinsky KE, Landefeld CS 1996; Davis A 1996; Eleazer GP, Hornung CA 1996; Hakim RB, Teno JM 1996; Hamel MB, Phillips RS 1996; Miles SH, Koepf R 1996; Murphy ST, Palmer JM 1996; Teno JM, Lynn J 1996; Cleary JF, Carbone PP 1997; Galanos AN, Pieper CF 1997; Hauser JM, Kleefeld SF 1997; Hofmann JC, Wenger NS 1997; Mor V, Intrator O 1997; Teno J, Lynn J 1997; Bradley EH, Peiris V 1998; Hammes BJ, Rooney BL 1998; Morrison RS, Zayas LH 1998; Teno JM, Stevens M 1998; Carmin CN, Pollard CA 1999; Hamel MB, Davis RB 1999; Hamel MB, Teno JM 1999; Hamel

MB, Lynn J 2000;Teno JM, Fisher E 2000;Teno JM, Harrell FE, Jr. 2000;Walsh D, Donnelly S 2000;Wenger NS, Phillips RS 2000;Wu AW, Yasui Y 2000;Happ MB, Capezuti E 2002;Kolarik RC, Arnold RM 2002;Schwartz CE, Wheeler HB 2002;Yurk R, Morgan D 2002;Allen RS, DeLaine SR 2003;Clarfield AM, Gordon M 2003;Mitchell SL 2003;Scott JT, Harmsen M 2003)

35. **Assessing and treating children as patients and as family members:** (McCullough PK 1992;Perrin JM, Shayne, M., and Bloom, S 1993;McCue K 1994;Mayo S 1996;Sourkes BM 1996;Kunin H 1997;Carmin CN, Pollard CA 1999;International Work Group on Death, Dying, and Bereavement, Work Group on Palliative Care for Children 1999;American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care 2000;Collins JJ, Byrnes ME 2000;Sahler OJ, Frager G 2000;Wolfe J 2000;Wolfe J, Grier HE 2000;Armstrong-Dailey A,Zarbock S 2001;Hinds PS, Oakes L 2001;Brown-Hellsten M, Hockenberry-Eaton M 2002;Collins JJ 2002;Rauch P,Arnold R 2002;Rauch PK, Muriel AC 2002;Depaola SJ, Griffin M 2003;Higginson IJ,Thompson M 2003;Scott JT, Harmsen M 2003;Solomon MZ, Browning D 2003;Tadmor CS, Postovsky S 2003) {ARE 3.3, 3.4; CCS 1.2, 1.3, 2.1, 3, 3.1- 3.3, 8, 10, 11, 13}

36. **Regular reassessment to recognize shifting and multiple priorities:** (American Society of Clinical Oncology End of Life Task Force 1998;Morita T, Tsunoda J 1999;American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care 2000;Emanuel EJ, Fairclough DL 2000;Billings JA, Block SD 2002;Hilden JM, Tobin DR 2002) {CC 2.2, 2.4, IDT 11.2, 12, 12.1-12.4; CCS 1-15, 15.1}

37. **Access to specialists:** (Giordano M 2000;Friedman BT, Harwood MK 2002;Hanks GW, Robbins M 2002;Payne S,Haines R 2002;Lloyd-Williams M 2003;Miller SC, Kinzbrunner B 2003){CSS 5.4; IDT 6}

38. **Involve patient and family, community resources, and other supports in developing and carrying out the care plan. Palliative care programs coordinate and collaborate with hospice and other community programs, including referrals to community resources (school, work, transportation, rehabilitation, assistance with obtaining medications and medical equipment, financial support):** (Mor V 1987;Mor V, Greer DS 1988;Tulsky JA,Lo B 1992;Tulsky JA,Fox E 1996;Dowdy MD, Robertson C 1998;Schneiderman LJ, Gilmer T 2000;Friedman BT, Harwood MK 2002;Hanks GW, Robbins M 2002;Meier D. E. 2002;von Gunten CF 2002a;Lee S,Kristjanson L 2003;Miller SC, Kinzbrunner B 2003;Schneiderman LJ, Gilmer T 2003;Cassidy JP,Davies DJ 2004) { RE 1.4; CCS 5.4;IDT 6, 6.3; CCS 14, 14.1, 14.2} {IDT 6, 6.3; 7.1, 11.1; CCS 14, 14.1, 14.2 Change to 53}

39. **Documentation of assessment and care plan:** (Higginson I,McCarthy M 1989;Bruera E, Kuehn N 1991;Du Pen SL, Du Pen AR 1999;Collins JJ, Byrnes ME 2000;Nelson JE, Meier DE 2001;Tranmer JE, Heyland D 2003) {ARE 8; CC1.1, 2, 2.3; IDT 12.1, 12.4, 13.3; MI 3.3}

40. **Services are available 24-hours-a-day, 7-days-a-week:** (Lynn J, Schuster JL 2000) {CC 1, 1.1-1.3, 1.5; HIF CCS 2; HFCF CCS 1, 1.1, 1.2, 2; NF ARE, 1.1}

41. **Respite services are available:** (Cumming M 1993;Ingleton C, Payne S 2003)

42. **Overall review of care occurs in weekly team meetings, while regular meetings allow for discussion of quality of care:** {IDT 12.1, 12.2, 15.5; HR 1.1}

43. **Team leaders are trained for their role:** {LG 8.2, 12; HR 9.2}

44. **Policies for timely intake are documented:** {CC 2.1; MI 1.1, 1.2}

45. **Volunteers may be included:** (Mount BM 1992;Craig M 1994;Fusco-Karmann C, Gangeri L 1996;Lemkin P 2001;Doyle D 2003){HR 7.5}

46. **Staff are supported in obtaining ongoing professional education, including discipline-specific training:** (Mount BM 1986;Block SD,Billings JA 1995;Brown-Saltzman K 1998;Ferrell BR, Virani R 1998;Miller PJ, Hedlund SC 1998;Christ GH,Sormanti M 1999;Ferrell B, Virani R 1999a;Ferrell B, Virani R 1999b;Ferrell B. R., Grant M. 1999;Ferrell BR, Juarez G 1999;Saunderson EM,Ridsdale L 1999;Csikai EL,Bass K 2000;Ferrell BR, Virani R 2000;Ferrell BR, Virani R 2000;Reese D, Raymer M 2000;Meier DE, Back AL 2001;Roff S 2001;American College of Surgeons 2002;Back AL, Starks H 2002;Ferrell BR,Borneman T 2002;Leipzig RM, Hyer K 2002;Hospice and Palliative Nurses Association 2004b;Hospice and Palliative Nurses Association 2004a;Monroe B 2004) {HR 3.5, 3.6, 4, 4.1-4.5, 5, 5.1- 5.4, 6, 6.1-6.3, 7, 7.1, 7.2, 9, 9.1, 9.2}

47. **Staff support is provided, including regular meetings:** (Smith SP,Varoglu G 1985;Vachon MS 1995;Vachon ML 1998;Kristjanson LJ, McPhee I 2001;Vachon MLS 2004) {HR 4.5}

48. **For care outside the home, patients and families are provided with a safe, home-like atmosphere that allows for privacy, cooking, visiting at all times, and access for children:** {HIFCCS 3; HIFCSIC 1,1.1-1.7, 5; HRCFSIC 1, 1.1-1.9, 2, 2.1-2.6, 3, 3.1, 5, 7, 7.1-7.4}

Domain 2: Physical Aspects of Care

I. PAIN

49. **Pain in end-of-life care:** (Bruera E, Carraro S 1986; Brenneis C, Michaud M 1987; Ventafridda V, Ripamonti C 1987; Berde C, Ablin A 1990; Ripamonti C, Bruera E 1991; Zaw-Tun N, Bruera E 1992; Portenoy RK 1993; Ferrell BR, Rhiner M 1994a; Ferrell BR, Rhiner M 1994b; Jacox A., Carr D. B. 1994; Jacox A., Carr D.B. 1994; Portenoy RK, Thaler HT 1994; Collins JJ, Grier HE 1995; Portenoy RK 1995; Vigano A, Fan D 1996; World Health Organization 1996; Lawlor P, Turner K 1997; Lawlor P, Walker P 1997; Lynn J, Teno JM 1997; Portenoy RK 1997b; Portenoy RK 1997a; Ripamonti C, Zecca E 1997; Lawlor PG, Turner KS 1998; Morrison RS, Ahronheim JC 1998; Ripamonti C, De Conno F 1998; Vigano A, Bruera E 1998; World Health Organization 1998a; McCaffery M, Pasero C 1999; American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care 2000; Milch RA 2000; Thorns A, Sykes N 2000; Zekry HA, Bruera E 2000; Zeppetella G 2000; Abraham J 2001; Coluzzi PH, Schwartzberg L 2001; Greenstreet W 2001; McCracken LM, Matthews AK 2001; Mitten T 2001; American Association of Colleges of Nursing 2002; Choi YS, Billings JA 2002; Mercadante S, Radbruch L 2002; National Institute of Health Consensus Development Program 2002; Radbruch L, Sabatowski R 2002; Ripamonti C, Bianchi M 2002; Smith TJ, Staats PS 2002; Thompson G, McClement S 2002; Briggs M, Nelson EA 2003; Mailis A, Furlan A 2003; Quigley C, Wiffen P 2003; Ribeiro MDC, Zeppetella G 2003; Sittl R, Griessinger N 2003; Zeppetella G, Ribeiro M 2003) {CCS 1, 1.2, 1.3, 2, 2.1, 2.5, 3, 3.1, 3.2, 10, 14; IDT 11.2, 12, 12.1, 12.2, 12.3, 12.4; MI 3.3}

50. **Pain assessment:** (Portenoy RK, Hagen NA 1990; Fothergill-Bourbonnais F, Wilson-Barnett J 1992; Johnston CC, Stevens B 1993; Parmelee PA, Smith B 1993; Savedra MC, Holzemer WL 1993; Bruera E 1994; Ferrell BA 1995; Bruera E, Pereira J 1996; Parmelee PA 1996; Merkel S, Voepel-Lewis T 1997; Portenoy RK 1997a; Chambers CT, Reid GJ 1998; Ferrell BR, Virani R 1998; Morrison RS, Ahronheim JC 1998; Portenoy RK, Lesage P 1999; Collins JJ, Byrnes ME 2000; Francke LS, Greenberg CS 2000; Joint Commission on Accreditation of Healthcare Organizations 2000; Sulmasy DP, Ury WA 2000; American Academy of Pediatrics. Committee on Psychosocial Aspects of Child and Family Health 2001; Breau LM, Camfield C 2001; Mercadante S, Portenoy RK 2001c; Mercadante S, Portenoy RK 2001a; Mercadante S, Portenoy RK 2001b; Collins JJ, Devine TD 2002; Bruera E, Castro M 2003; Miller SC, Kinzbrunner B 2003) {CCII.1,2; IDT 13.3}

51. **Pain treatment:** (Bruera E, Carraro S 1986; Brenneis C, Michaud M 1987; Bruera E, Brenneis C 1988; Bruera E 1991; Bruera E 1992; Walsh TD, MacDonald N 1992; Portenoy RK 1993; Bruera E 1994; Cleeland CS, Gonin R 1994; Jacox A., Carr D. B. 1994; Jacox A., Carr D.B. 1994; Breitbart W, Bruera E 1995; Portenoy RK 1995; Thomas Z, Bruera E 1995; Bozzetti F, Amadori D 1996; Breitbart W, McDonald MV 1996; Lipman AG 1996; Rosenfeld B, Breitbart W 1996; Watanabe S, Belzile M 1996; Cleeland CS, Gonin R 1997; Portenoy RK 1997b; Ripamonti C, Bruera E 1997; Ripamonti C, De Conno F 1997; Watanabe S, Carmody D 1997; Bernabei R, Gambassi G 1998; Watanabe S, Pereira J 1998; Du Pen SL, Du Pen AR 1999; Grossman SA, Benedetti C 1999; Manfredi PL, Shenoy S 2000; Tarumi Y, Watanabe S 2000; American Academy of Pediatrics. Committee on Psychosocial Aspects of Child and Family Health 2001; Cherny N, Ripamonti C 2001; Filiberti A, Ripamonti C 2001; Gibson J, Grealish L 2001; Manfredi PL, Gonzales GR 2001; American Geriatric Society Panel on Persistent Pain in Older Persons 2002; Barnes EA, Bruera E 2002; Barnes EA, Palmer JL 2002; Mercadante S, Villari P 2002; Moryl N, Santiago-Palma J 2002; Bell R, Eccleston C 2003; Harris JT, Suresh Kumar K 2003; Howard RF 2003; Kearns GL, Abdel-Rahman SM 2003; Lander JA, Weltman BJ, Lussier D 2003; Mailis A, Furlan A 2003; Martinez MJ, Roque M 2003a; Nicholson A, Davies AN 2003; Reid CM, Davies AN 2003; Ribeiro MDC, Zeppetella G 2003; Siden H, Nalewajek 2003; Tremont-Lukats IW, Teixeira GM; Wiffen P, Collins S; Zeppetella G, Ribeiro M 2003)

II. OTHER PHYSICAL SYMPTOMS

52. **Physical symptoms: general:** (Cassell ES 1982; Cassel CK 1984; Bruera E, Carraro S 1986; Brenneis C, Michaud M 1987; Bruera E, Brenneis C 1988; Ventafridda V, Ripamonti C 1990; Bruera E, Fainsinger R 1991; Bruera E 1992; Addington-Hall J, Lay M 1995; Bozzetti F, Amadori D 1996; Cleary JF, Carbone PP 1997; Conill C, Verger E 1997; Hearn J, Higginson IJ 1997; McClement SE, Woodgate RL 1997; Neuenschwander H, Bruera E 1997; Campbell M 1998; Ng K, von Gunten CF 1998; O'Brien T, Welsh J 1998; World Health Organization 1998b; Cassell EJ 1999; Emanuel LL, von Gunten CF 1999; Ferrell B.R., Grant M. 1999; Kemp C 1999; Shuster JL, Jr., Breitbart W 1999; Twycross R 1999; Wrede-Seaman L 1999; Bednash G, Ferrell B 2000; Bernard SA, Bruera E 2000; Collins JJ, Byrnes ME 2000; Keay TJ, Schonwetter RS 2000; Leland JY 2000; McCallum DE, Byrne P 2000; Waller A, Caroline NL 2000; Walsh D, Donnelly S 2000; Eilershaw J, Smith C 2001; Emanuel LL, Alpert HR 2001; Ferrell B, Coyle N 2001; Hermann C, Loonery S 2001; Matzo ML, Sherman DW 2001; Pierucci RL, Kirby RS 2001; Smith SA 2001; Berger A, Portenoy RK 2002; Coll PP, Duffy JD 2002; Pantilat SZ 2002; World Health Organization 2002; Abraham JL 2003; Drake R, Frost J 2003; Eilershaw J, Ward C 2003; Keay TJ, Alexander C 2003; Parker RG, Janjan NA 2003; Pinderhughes ST, Morrison RS 2003; Ripamonti C, Brunelli C 2003; Schapiro R, Byock I 2003; Tranmer JE, Heyland D 2003; Woodgate RL, Degner LF 2003; Buckley G, Smyth A 2004) {IDT 5.1; CCS6,11,13,13.1, 13.2, 14, 14.1, 14.2}

53. **Anorexia/cachexia:** (Bruera E, Carraro S 1986; Bruera E, Chadwick S 1986; Bruera E, Brenneis C 1988; Bruera E, Macmillan K 1990; Bruera E 1994; Vigano A, Watanabe S 1994; Von Roenn JH, Armstrong D 1994; Watanabe S, Bruera E 1994; Kotler DP, Grunfeld C 1995; Bozzetti F, Amadori D 1996; Watanabe S, Bruera E 1996; Bruera E 1998b; Kotler DP 1998; Wood L, Palmer M 1998; Amigo P, Mazuryk ME 2000; Bernard SA, Bruera E 2000; Bruera E, Sweeney C 2000; Kotler LA, Walsh BT 2000; Strasser F, Bruera ED 2002; Berenstein EG, Ortiz Z; Bruera E, Castro M 2003)

54. **Anxiety:** (Bruera E, Carraro S 1986;Butters E, Higginson I 1992;Butters E, Higginson I 1993;Maguire P, Faulkner A 1993;Ibbotson T, Maguire P 1994;Breitbart W, Bruera E 1995;Ginsburg ML, Quirt C 1995;Massie MJ,Payne DK 1999;Shuster JL, Jr., Breitbart W 1999;2000;Payne DK,Massie MJ 2000;Pasacreta J, Minarik P 2001;Breitbart W, Chochinov HM 2004)
55. **Delirium:** (Brenneis C, Michaud M 1987;Bruera E 1991;Stiefel F,Bruera E 1991;Stiefel F, Fainsinger R 1992;Harrison J, Maguire P 1994;Yue M, Fainsinger RL 1994;Breitbart W, Marotta R 1996;Boyle DM, Abernathy G 1998;Lawlor PG, Watanabe S 1998;Shuster JL, Jr., Breitbart W 1999;Breitbart W,Cohen K 2000;Lawlor PG, Fainsinger RL 2000;Lawlor PG, Gagnon B 2000;Lawlor PG, Nekolaichuk C 2000;Kuebler KK, English N 2001;Barnes EA, Palmer JL 2002;Breitbart W, Gibson C 2002;Breitbart W, Tremblay A 2002;Ingham J,Caraceni A 2002;Lawlor PG,Bruera ED 2002;Caraceni A,Grassi L 2003;Breitbart W, Chochinov HM 2004)
56. **Depression:** (Hardman A, Maguire P 1989;Hopwood P, Howell A 1991b;Hopwood P, Howell A 1991a;Depression Guideline Panel 1993;Block SD,Billings JA 1994;Fallowfield LJ, Hall A 1994;Ford S, Fallowfield L 1994;Ibbotson T, Maguire P 1994;Billings JA 1995;Breitbart W, Bruera E 1995;Vigano A, Watanabe S 1995;Chochinov HM, Wilson KG 1998;Ganzini L, Johnston WS 1998;Miller PJ, Hedlund SC 1998;Covinsky KE, Kahana E 1999;Massie MJ,Payne DK 1999;Shuster JL, Jr., Breitbart W 1999;Block SD,Panel for the American College of Physicians-American Society of Internal Medicine End-of-Life Care Consensus Panel 2000;U.S. Preventive Services Task Forces 2000;Wilson KG, Chochinov HM 2000;Block S. D. 2001;Breitbart W, Rosenfeld B 2001;Lloyd-Williams M,Friedman T 2001;Nelson JE, Meier DE 2001;Filiberti A,Ripamonti C 2002;Lloyd-Williams M 2002;National Institute of Health Consensus Development Program 2002;Nelson CJ, Rosenfeld BJ 2002;Breitbart W, Chochinov HM 2004)
57. **Dyspnea and other respiratory symptoms:** (Rueben DB,Mor V 1986;Ajemian I 1991;Bruera E, de Stoutz N 1993;Bruera E, MacEachern T 1993;Bruera E 1994;Addington-Hall J, Lay M 1995;Bennett MI 1996;Corner J, Plant H 1996;Kuebler KK, Dahlin C 1996;Adam J 1997;Boyd KJ,Kelly M 1997;Ripamonti C,Bruera E 1997;Rousseau P 1997;Ripamonti C, Fulfaro F 1998a;Zepetella G 1998;American Thoracic Society 1999;Bruera E, Belzile M 1999;Ripamonti C 1999;Schwartzstein RM 1999;Bruera E, Schmitz B 2000;Dudgeon DJ, Kristjanson L 2001;Barnes EA, Palmer JL 2002;Cohen SP,Dawson TC 2002;Coyne PJ, Viswanathan R 2002;Ripamonti C,Fusco F 2002;Shimoyama N,Shimoyama M 2002;Spector N,Klein D 2002;Agarwal R,Shaw P,Jennings AL, Davies AN 2003)
58. **Fatigue:** (Bruera E, Brenneis C 1988;Breitbart W, Bruera E 1995;Ferrell BR, Grant M 1996;Monti M, Castellani L 1996;Kaasa T, Loomis J 1997;Vogelzang NJ, Breitbart W 1997;Breitbart W, McDonald MV 1998;Cella D, Peterman A 1998;Barroso J 1999;Grant M, Golant M 2000;Krishnasamy M 2000;Liao S,Ferrell BA 2000;Mock V, Atkinson A 2000;Oyama H, Kaneda M 2000;Porock D, Kristjanson LJ 2000;Adinolfi A 2001a;Adinolfi A 2001b;Bormann J, Shively M 2001;Breitbart W, Rosenfeld B 2001;Cella D, Davis K 2001;Given CW, Given B 2001;Lee KA, Portillo CJ 2001;Miramontes H 2001;Barnes EA,Bruera E 2002;Barroso J,Lynn MR 2002;National Institute of Health Consensus Development Program 2002;Passik SD, Kirsh KL 2002)
59. **Gastrointestinal:** (Bruera ED, Roca E 1983;Bruera E, Jackson FI 1985;Brenneis C, Michaud M 1987;Bruera E, Brenneis C 1988;Bruera E 1994;Bozzetti F, Amadori D 1996;Baines MJ 1997;Oneschuk D,Bruera E 1997;Amigo P, Mazuryk ME 2000;Mercadante S, Ripamonti C 2000;Wenk R, Bertolino M 2000;Ripamonti C, Twycross R 2001;Choi YS,Billings JA 2002;Filiberti A,Ripamonti C 2002;Ahmed N, Ahmedzai S 2003;Feuer DJ,Broadley KE 2003;Goodman ML,Wilkinson S 2003;Westby MJ 2003)
60. **Genitourinary:** (Smith P,Bruera E 1995;Gray M,Campbell FG 2001;Norman RW,Bailly G 2004)
61. **Hiccups:** (Kolodzik PW,Eilers MA 1991;Ramirez FC, Graham, D.Y 1992;Bruera E, MacEachern T 1993;Okuda Y, Kitajima T, Asai T 1998;Walker P, Watanabe S 1998;Lewis JH 2000)
62. **Mucositis/stomatitis/xerostomia:** (De Conno F, Ripamonti C 1989;Rothwell BR,Spektor WS 1990;Guchelaar HJ, Vermes A 1997;Sweeney MP, Bagg J 1997;Bruera E 1998c;Sweeney MP, Bagg J 1998;Oneschuk D, Hanson J 2000c; Dahlin C, Goldsmith T 2001;Borbasi S, Cameron K 2002;Shih A, Miaskowski C 2002;Deane K, Whurr R 2003; Clarkson JE, Worthington HV 2003)
63. **Nutrition/hydration:** (Billings JA 1985;Bruera E, Brenneis C 1988;Bruera E, Brenneis C 1989;Yan E,Bruera E 1991;Bruera E 1994;Bozzetti F, Amadori D 1996;Bruera E, Belzile M 1996;Mitchell SL, Kiely DK 1997;Mitchell SL, Kiely DK 1998;Steiner N,Bruera E 1998;Covinsky KE, Martin GE 1999;Bruera E 2001;Gessert CE,Calkins DR 2001;Sarhill N, Walsh D 2001;Guggenheimer J,Moore PA 2003;Mitchell SL 2003)
64. **Skin care:** (Payne RL,Martin ML 1990;Camp-Sorrell D 1991;O'Rourke ME 1991;U.S. Agency for Health Care Policy and Research 1992;Payne RL,Martin ML 1993;Schulte MJ 1993;Femia C,Smith R 1994;Seaman S 1995;Tumberello J 1995;Ayello EA 1997;Haisfield-Wolfe ME,Rund C 1997;Baranoski S, Salzberg CA 1998;Ayello EA 1999;Ayello EA, Thomas DR 1999;Baranoski S 1999;Goebel RH,Goebel MR 1999;Haisfield-Wolfe ME,Baxendale-Cox LM 1999;Ayello EA 2000;Baranoski S 2000b;Baranoski S 2000a;Grocott P 2000;Hampton S 2000;Maffei A, Ayello J 2000;2000;Grocott P,Cowley S 2001;Trent JT,Kirsner RS 2001;Wilkes L, White K 2001;Ayello EA,Braden B 2002;Ayello EA, Cuddigan J 2002;Baldwin KM 2002;Belmin

J, Meaume S 2002;Froiland KG 2002;Hess CT 2002;Holloway S, Bale S 2002;Yoshikawa TT 2002;Baranoski S,Thimsen K 2003;Bosonnet L 2003;Henoch I,Gustafsson M 2003;Odierna E,Zeleznik J 2003;Pigginc C 2003;Trent JT,Kirsner RS 2003a;Trent JT,Kirsner RS 2003b)

65. **Sleep disturbance/insomnia:** (Gibson J,Grealish L 2001;Hirst A,Sloan R 2002)

III. ORGAN DYSFUNCTION

66. **Bone metastases:** (Oneschuk D,Bruera E 1996;Fulfaro F, Casuccio A 1998;Ripamonti C, Fulfaro F 1998b;Barton MB, Dawson R 2001;Ripamonti C,Fulfaro F 2001;Martinez MJ, Roque M 2003a;Martinez MJ, Roque M 2003b)

67. **Cardiac disease:** (Konstam M, Dracup K 1994;Burns RB, McCarthy EP 1997;Wolinsky FD, Overhage JM 1997;Wolinsky FD, Smith DM 1997;Krumholz HM, Phillips RS 1998;Maddocks I 1998;Goodlin SJ, Zhong Z 1999;Leland JY 2000;Levenson JW, McCarthy EP 2000;Anderson H, Card C 2001;Flowers B 2003;Mueller PS, Hook CC 2003;Nordgren L,Sorensen S 2003)

68. **Dementia:** (Ferrell BA 1995;McCarthy M, Addington-Hall J 1997;Teno JM, Landrum K 1997;O'Brien T, Welsh J 1998;Solomon MZ,Jennings B 1998;Finucane TE, Christmas C 1999;Lynn J, Teno J 1999;Volicer L 1999;Hurley AC, Volicer L 2000;Volicer L 2001;Volicer L, Hurley AC 2001;Evers MM, Purohit D 2002;Hurley AC,Volicer L 2002;Boult L, Dentler B 2003;Manfredi PL, Breuer B 2003;Volicer L, Hurley AC 2003)

69. **Endocrine/metabolic disorders:** (Markell MS,Friedman EA 1990;Kovacs CS, MacDonald SM 1995;Walker P, Watanabe S 1996;Walker P, Watanabe S 1997;Rajagopal A, Kala S 2003)

70. **Liver disease:** (Bolder U, Brune A 1999;Roth K, Lynn J 2000;Kimoto T, Yamanoi A 2001;Riley TR, 3rd,Bhatti AM 2001a;Riley TR, 3rd,Bhatti AM 2001b;Riley TR, 3rd, Chinchilli VM 2001;Donckier V, Van Laethem JL 2003;Testa R, Testa E 2003)

71. **Neurological disease:** (Borasio GD,Voltz R 1997;Smyth A, Riedl M 1997;Borasio GD,Voltz R 1998;Carter GT,Miller RG 1998;Ganzini L, Johnston WS 1998;Carver AC, Vickrey BG 1999;Ganzini L, Johnston WS 1999;Parker D, Maddocks I 1999;Oliver D, Borasio GD 2000;Ben-Zacharia AB,Lublin FD 2001;Borasio GD, Shaw PJ 2001;Foley KM,Carver AC 2001;Mandler RN, Anderson FA, Jr. 2001;Bradley WG 2002)

72. **Pulmonary conditions:** (Bruera E 1990;Gentile VG,Isaacson G 1996;von Gunten CF,Twaddle ML 1996;Hansen-Flaschen J 1997;Kesten S 1997;Lord E 1997;Robinson WM, Ravilly S 1997;Haddad A 1998;Tonelli MR 1998;Westwood AT 1998;Acres JC 2000;Claessens MT, Lynn J 2000;Hansen-Flaschen JH 2000;Heffner JE 2000;Hodson ME 2000;Levy MM 2000;Lynn J, Ely EW 2000;Mitchell I, Nakielna E 2000;Edmonds P, Karlsen S 2001;Ferrin M, Happ MB 2001;Hansen-Flaschen JH 2003)

73. **Renal disease:** (Neu S,Kjellstrand CM 1986;Campbell ML 1991;Cohen LM, McCue JD 1995;Henderson ML 1995;Hamel MB, Phillips RS 1997;Mesler DE, Byrne-Logan S 1999;Cohen LM, Germain MJ 2003;Poppel DM, Cohen LM 2003)

III. OTHER SYMPTOM CONTROL TOPICS

74. **HIV/AIDS:** (Expert Working Group on Integrated Palliative Care for Persons with AIDS 1988;Corless IB, Fulton R 1992;Butters E, Higginson I 1993;Goldstone I 1995;Grothe TM,Brody RV 1995;Kemp C,Stapp L 1995;McKeogh M 1995;Fantoni M, Ricci F 1997;O'Neill JF,Alexander CS 1997;Wood CG, Whittet S 1997;Ropka M,Williams A 1998;Meyer M 1999;Newshan G,Sherman DW 1999;Vogl D, Rosenfeld B 1999;Witteveen PO, Jacobs HM 1999;Corless IB,Nicholas PK 2000;Greenberg B, McCorkle R 2000;Nicholson J,Turner N 2000;O'Neill JF, Marconi K 2000;Maartens G, Bekker LG 2001;Matheny SC 2001;Coyn PJ, Lyne ME 2002;Karasz A, Dyche L 2003;O'Neill JF,Marconi K 2003;O'Neill JF, Selwyn PA 2003;Selwyn PA,Forstein M 2003)

75. **Emergencies:** (Baines MJ 1997;Boyd KJ,Kelly M 1997;Falk S,Fallon M 1997;Gagnon B,Bruera E 1998;Gagnon B, Mancini I 1998;Abraham JL 1999;Ripamonti C 1999;Mercadante S, Villari P 2002;Ripamonti C,Fusco F 2002;Jennings AL, Davies AN 2003;Saunders Y, Ross JR 2003)

76. **Trauma:** (Campbell ML, Frank RR 1997;American Academy of Pediatrics and the American College of Emergency Physicians 2002;Seward E, Greig E 2003)

77. **Care in the ICU:** (Shortell SM, Zimmerman JE 1994;Keenan SP, Busche KD 1997;Lynn J, Harrell F, Jr. 1997;Prendergast TJ,Luce JM 1997;Dowdy MD, Robertson C 1998;Glance LG, Osler T 1998;Keenan SP, Busche KD 1998;Danis M, Federman D 1999;Burns JP, Mitchell C 2000;Ostermann ME, Keenan SP 2000;Schneiderman LJ, Gilmer T 2000;Teno JM, Fisher E 2000;Burns JP, Mitchell C 2001;Curtis JR,Rubinfeld GD 2001;Puntillo KA, Benner P 2001;Rubinfeld GD, Randall Curtis J 2001;Baggs JG 2002;Catlin A,Carter B 2002;Campbell ML,Guzman JA 2003;Schneiderman LJ, Gilmer T 2003)

78. **Pharmacology issues:** (Bruera E, Roca E 1985;Ripamonti C,Bruera E 1991;Bernard SA,Bruera E 2000;Peuckmann V, Fisch M 2000;Choi YS,Billings JA 2002;Ripamonti C,Bianchi M 2002;Ripamonti C, Sweeney C 2002)

79. **Complementary medicine:** (Bruera E, Fainsinger R 1995;Finlay IG,Jones OL 1996;Bruera E 1998a;Jenkins CA, Scarfe A 1998;Oneschuk D, Fennell L 1998;Cassileth BR 1999;Decker GM 1999;Oneschuk D,Bruera E 1999;Abel J 2000;Davieson BA,Kennelly J 2000;Nield-Anderson L,Ameling A 2000;Oneschuk D, Hanson J 2000a;Paice JA, Ferrans CE 2000;Paice JA, Ferrans CE 2000;National Hospice and Palliative Care Organization 2001a;Demmer C,Sauer J 2002;Langenfeld MC, Cipani E 2002;Zeltzer LK, Tsao JC 2002;Brenner ZR,Krenzer ME 2003;Garnett M 2003;Hilliard RE 2003;Buckle S 2003;Manfredi PL,Gonzales GR 2003;Sanders H, Davis MF 2003;Schofield P,Payne S 2003)

80. **Standardized instruments of assessment:** (Cohen SR, Mount BM 1996b;Neuenschwander H, Bruera E 1997;Teno JM, Byock I 1999;Donnelly S 2000;Teno J 2000;Anandarajah G,Hight E 2001;Novak B, Kolcaba K 2001;Teno JM, Casey VA 2001;Volicer L, Hurley AC 2001;Cohen SR,Leis A 2002;Passik SD, Kirsh KL 2002;Sulmasy DP 2002;Deeken JF, Taylor KL 2003;McClain CS, Rosenfeld B 2003)

Domain 3: Psychological and Psychiatric Aspects of Care

81. **Psychological distress in death and dying:** (Maguire P 1985;Devlen J, Maguire P 1987a;Devlen J, Maguire P 1987b;Miller RD,Walsh TD 1991;Dunn SM, Patterson PU 1993;Evans AJ 1994;Parle M, Jones B 1996;Davis CG, Nolen-Hoeksema S 1998;Doka KJ 1998;National Comprehensive Cancer Network 1999;Emanuel EJ, Fairclough DL 2000;Greenstein M,Breitbart W 2000;Powazki RD, Palcisco C 2000;Rando TA 2000;Steinhauser KE, Clipp EC 2000;Kornblith AB, Herndon JE 2001;Teno JM, Casey VA 2001;Yedidia MJ,MacGregor B 2001;Jansen LA,Sulmasy DP 2002a;Werth JL, Jr., Gordon JR 2002;Kissane DW, McKenzie M 2003;National Comprehensive Cancer Network 2003a;Pitceathly C,Maguire P 2003)

82. **Professionals with training and skills in providing appropriate care to diverse patient populations:** (Haines A,Booroff A 1986;Maguire P 1990;Caldwell J,Scott JP 1994;Chevrier F, Steuer R 1994;Maguire P, Booth K 1996;Maguire P, Faulkner A 1996;Scott JP,Caldwell J 1996;Parle M, Maguire P 1997;Seely JF, Scott JF 1997;Sherry KL, Bruera E 1997;Maguire P, Walsh S 1999;Lemkin P 2001;Payne S 2001;Leipzig RM, Hyer K 2002)

83. **Assessment of psychological reactions:** (Robbins RA 1991;Ginsburg ML, Quirt C 1995;Taube AW, Jenkins C 1997;Rousseau P 2000b;Block SD 2001;Roberts S, Black C 2002)

84. **Treatment of psychiatric symptoms and use of tools:** (Depression Guideline Panel 1993;Prigerson HG, Maciejewski PK 1995;Kissane DW, Bloch S 1997;Bernabei R, Gambassi G 1998;Lawlor PG, Watanabe S 1998;Lawlor PG, Nekolaichuk C 2000;Teno JM, Harrell FE, Jr. 2000;U.S. Preventive Services Task Forces 2000;Kuebler KK, English N 2001;Lloyd-Williams M 2001;Breitbart W, Gibson C 2002;National Institute of Health Consensus Development Program 2002;Brodsky H, Green A 2003;Caraceni A,Grassi L 2003;National Comprehensive Cancer Network 2003a) {NHPCO: IDT}

85. **Quality of life in end stage diseases, including measurement tools:** (Higginson I, Wade A 1990;Bruera E, Kuehn N 1991;Cohen SR,Mount BM 1992;Higginson IJ,McCarthy M 1994;Cohen SR, Mount BM 1995;Wu AW, Damiano AM 1995;Cohen SR, Mount BM 1996a;Cohen SR, Mount BM 1996b;Cohen SR, Bultz BD 1997;Cohen SR, Mount BM 1997;Greisinger AJ, Lorimor RJ 1997;Hearn J,Higginson IJ 1997;Lynn J 1997;Neuenschwander H, Bruera E 1997;Rudberg MA, Teno JM 1997;Chang VT, Thaler HT 1998;Donaldson MS,Field MJ 1998;Smeenk FW, van Haastregt JC 1998;Tierney RM, Horton SM 1998;Axelsson B,Sjoden PO 1999;Brady MJ, Peterman AH 1999;Singer P, Martin DK 1999;Singer PA, Martin DK 1999a;Singer PA, Martin DK 1999b;Stewart AL, Teno J 1999;Teno JM, Byock I 1999;Cohen SR,Mount BM 2000;Donnelly S 2000;Gabany JM 2000;Steinhauser KE, Christakis NA 2000;Steinhauser KE, Clipp EC 2000;Tolle SW, Tilden VP 2000;Cohen SR, Boston P 2001;DeSilva DL, Dillon JE 2001;Hickman SE, Tilden VP 2001;Sahlberg-Blom E, Ternstedt BM 2001;Chochinov HM, Hack T 2002a;Cohen SR,Leis A 2002;Contro N, Larson J 2002;Grant M,Hanson J 2002;Miller SC, Mor V 2002;Miller SC,Mor VN 2002;Steinhauser KE, Bosworth HB 2002;Steinhauser KE, Clipp EC 2002;Thompson G,McClement S 2002;Vig EK, Davenport NA 2002;Aspinal F, Addington-Hall J 2003;Llobera J, Esteva M 2003;Miller SC, Mor V 2003;Patrick DL, Curtis JR 2003;Scott JT, Harmsen M 2003;Tranmer JE, Heyland D 2003;Vig EK,Pearlman RA 2003)

86. **Assessment of patient coping and support:** (Maguire P, Hopwood P 1985;Vachon ML, Kristjanson L 1995;Chapman KJ,Pepler C 1998;Doka KJ 1998;Kavanaugh KM 1998;Roy DJ 1998;Russell P,Sander R 1998;Prigerson HG,Jacobs SC 2001;Yedidia MJ,MacGregor B 2001)

87. **Assessment of family coping and support:** (Sheehan CJ 1985;Bascom PB,Tolle SW 1995;Kelly B, Edwards P 1999;Bartel DA, Engler AJ 2000;Hockley J 2000;Thielemann P 2000;Andrews SC 2001;Wogrin C 2001;Main J 2002;Patterson LB,Dorfman LT 2002;Brazil K, Bedard M 2003;Brodsky H, Green A 2003;Dawson S,Kristjanson LJ 2003;Deeken JF, Taylor KL 2003;Kissane DW, McKenzie M 2003;Volicer L, Hurley AC 2003) See also caregiver burden (21)

88. **Grief and bereavement in various patient populations:** (Rando TA 1984;Kane RL, Klein SJ 1986;McIntyre BB 1990b;Couldrick A 1992;Levy LH, Derby JF 1993;Rando TA 1993;Payne S,Relf M 1994;Prigerson HG, Reynolds CF, 3rd 1994;Prigerson HG, Frank E 1995;Prigerson HG, Maciejewski PK 1995;Brown LF, Reynolds CF, 3rd 1996;Connor

SR, McMaster JK 1996; Jacob SR 1996; Prigerson HG, Bierhals AJ 1996; Prigerson HG, Shear MK 1996; Rosenzweig AS, Pasternak RE 1996; Frank E, Prigerson HG 1997; Gillance H, Tucker A 1997; Hall M, Buysse DJ 1997; Kissane DW, McKenzie DP 1997; Pasternak RE, Prigerson H 1997; Prigerson HG, Bierhals AJ 1997; Prigerson HG, Shear MK 1997; Rozenzweig A, Prigerson H 1997; Szanto K, Prigerson H 1997; Brown-Saltzman K 1998; Corr CA, Corr DM 1998; Davis CG, Nolen-Hoeksema S 1998; Hall M, Baum A 1998; Schlernitzauer M, Bierhals AJ 1998; van Doorn C, Kasl SV 1998; Zygmunt M, Prigerson HG 1998; Chen JH, Bierhals AJ 1999; Potts S, Farrell M 1999; Prigerson HG, Bridge J 1999; American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health 2000; Christ GH 2000; Cuthbertson SJ, Margetts MA 2000; Prigerson HG, Maciejewski PK 2000; Rando TA 2000; Casarett D, Kutner JS 2001; Corless IB 2001; Payne S 2001; Prigerson HG, Jacobs SC 2001; Silverman GK, Johnson JG 2001; Barry LC, Kasl SV 2002; Barry LC, Prigerson HG 2002; Christ GH, Bonanno G 2002; Christ GH, Siegel K 2002; Kirk K, McManus M 2002; Pearce MJ, Chen J 2002; Prigerson HG 2002; Rawlings D, Glynn T 2002; Rynearson EK, Favell JL 2002; LeBrocq P, Charles A 2003; O'Connor M, Nikolett S 2003; Kissane DW 2004)

89. **Grief and bereavement education for palliative care professionals:** (Rando TA 1984; Couldrick A 1992; Huart S, O'Donnell M 1993; Rando TA 1993; Corless IB, Germino B, Pittman M 1994; Brown CK 1995; Prigerson HG, Frank E 1995; Bouton BL 1996; American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health 2000; Barnes K 2001; Casarett D, Kutner JS 2001; Matsushima T, Akabayashi A 2002)

90. **Grief and bereavement education for families:** (Brown LF, Reynolds CF, 3rd 1996; Davis CG, Nolen-Hoeksema S 1998; Bartel DA, Engler AJ 2000; Casarett D, Kutner JS 2001; Ringdal GI, Jordhoy MS 2001; Ellison NM, Ptacek JT 2002; Kirk K, McManus M 2002; Prigerson HG 2002) {IDT 5.1, 6.3, 3.3}

91. **Bereavement support for children:** (McIntyre BB 1990a; McIntyre BB 1990b; Carroll ML, Griffin R 1997; Gillance H, Tucker A 1997; Cox G 1998; Davies B 1999; Potts S, Farrell M 1999; American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health 2000; Doka K 2000; Davies B 2001)

92. **Grief and bereavement risk assessment and reassessment:** (Payne S, Relf M 1994; Worden W 1996; Frank E, Prigerson HG 1997; Teno JM, Clarridge B 2001; Melliar-Smith C 2002) {BCS 2, 2.1, 2.2, 2.3, 3.4}

93. **Bereavement services:** (Bouton BL 1996; Hanson LC, Danis M 1997; Hoffman C 1997; Block SD 2001; Payne S 2001; Warren NA 2002; Schulz R, Mendelsohn AB 2003) {IDT 1.1; BCS 1}

94. **Staff support for those providing end-of-life care:** (Millison M, Dudley JR 1992; Higginson IJ, McCarthy M 1993; Harper B 1994; Vachon MS 1995; Davies B, Clarke D 1996; Maguire P, Booth K 1996; Vachon ML 1998; Barnes K 2001; Kristjanson LJ, McPhee I 2001; Leuthner SR, Pierucci R 2001; Puntillo KA, Benner P 2001; Yam BM, Rossiter JC 2001; Hanks GW, Robbins M 2002; Patterson LB, Dorfman LT 2002; Vachon MLS 2004) {BCS 4, 4.1, 4.1}

Domain 4: Social Aspects of Care

95. **Social assessment and care plan:** (Burrs FA 1995; Koenig BA, Gates-Williams J 1995; Davis A 1996; Eleazer GP, Hornung CA 1996; Hallenbeck J, Goldstein MK 1996; Koenig BA 1997; Morrison RS, Zayas LH 1998; Christ GH, Sormanti M 1999; Loudon RF, Anderson PM 1999; Emanuel EJ, Fairclough DL 2000; Hopp FP, Duffy SA 2000; Keovilay L, Rasbridge L 2000; Larson DG, Tobin DR 2000; Reese D, Raymer M 2000; Waters CM 2000; Curtis JR, Wenrich MD 2001; Contro N, Larson J 2002; Crawley LM, Marshall PA 2002; Wright EP, Kiely MA 2002; Seymour J 2003; Tong E, McGraw SA 2003) {IDT 1.1, 5.1, 11, 11.1-11.3; CCS 6, 6.1-6.3, 7, 7.1, 7.2, 9, 9.1-9.3, 10, 10.1-10.3, 11, 11.1, 11.3, 12, 12.1-12.2, 13, 13.1, 13.2, 14, 14.1, 14.2}

96. **Family structure and geographic location, relationships and intimacy, and communication in the family:** (Fins JJ, Solomon MZ 2001; Glajchen M, Zuckerman C 2001)

97. **Work and school**

98. **Finances:** (Covinsky KE, Goldman L 1994; Covinsky KE, Landefeld CS 1996; Emanuel EJ, Fairclough DL 2000)

99. **Sexuality:** (Chapman RM 1982; Rice A 2000; Rice AM 2000; Kaub-Wittemer D, Steinbuchel N 2003)

100. **Legal issues:** (Baluss ME 2002; Derse AR 2002)

101. **Routine patient and family meetings:** (Davis A 1996; Eleazer GP, Hornung CA 1996; Hallenbeck J, Goldstein MK 1996; Ambuel B 1999; Hallenbeck J, Goldstein MK 1999; Hopp FP, Duffy SA 2000; Larson DG, Tobin DR 2000; Curtis JR, Patrick DL 2001; Contro N, Larson J 2002; Scott JT, Harmsen M 2003)

Domain 5: Spiritual, Religious and Existential Aspects of Care

102. **Definitions: religious, spiritual, existential:** (Frankl V 1962; Cassell ES 1982; Grey A 1994; Kearney M, Mount BM 2000; Breitbart W 2002)

103. **Importance of spirituality for patients and families:** (Corless IB, Fulton R 1992; Oxman TE, Freeman DH, Jr. 1995; Taylor EJ, Amenta M 1995; Kark JD, Shemi G 1996; Kaldjian LC, Jekel JF 1998; Koenig HG, George LK 1998; Mytko JJ, Knight SJ 1999; Cox G 2000; Daaleman TP, VandeCreek L 2000; Rousseau P 2000c; Astrow AB, Puchalski CM 2001; Koenig HG 2001; Koenig HG, Larson DB 2001; Mueller PS, Plevak DJ 2001; Fife RB 2002; Koenig HG 2002; Nelson CJ, Rosenfeld BJ 2002; Steensma DP 2002; Mount BM 2003; Sheehan MN 2003; Taylor EJ 2003; Cassidy JP, Davies DJ 2004)

104. **Assessment of spiritual/religious/existential needs of patient and family, and related professional skills training:** (Taylor EJ, Amenta M 1995; Maugans TA 1996; Puchalski CM, Larson DB 1998; Baider L, Russak SM 1999; Cassell EJ 1999; Holland JC, Passik S 1999; Lo B, Quill T 1999; Sloan RP, Bagiella E 1999; Sulmasy DP 1999; Highfield ME 2000; Post SG, Puchalski CM 2000; Puchalski CM, Romer AL 2000; Sloan RP, Bagiella E 2000; Anandarajah G, Hight E 2001; Astrow AB, Puchalski CM 2001; Hermann CP 2001; Kornblith AB, Herndon JE 2001; Lo B, Ruston D 2002; Nelson CJ, Rosenfeld BJ 2002; Puchalski CM 2002; Sloan RP, Bagiella E 2002; Sulmasy DP 2002; McClain CS, Rosenfeld B 2003) {IDT 7, 7.1, 11, 11.2}.

105. **Responding to spirituality: interventions and their outcomes:** (Levin JS, Larson DB 1997; Sumner CH 1998; Block SD 2001; Hebert RS, Jenckes MW 2001; Sulmasy DP 2001; Roberts L, Ahmed I 2003)

106. **Cultural sensitivity to religious preferences:** (Crawley L, Payne R 2000; Highfield ME 2000; Sherman AC, Simonton S 2001; Kagawa-Singer M 1998; Kagawa-Singer M 2001; Krakauer EL, Crenner C 2002; Moadel A, Morgan C 1999) {IDT 7.1}

107. **Sensitive use by institutions of religious symbols, while patients/families display their own symbols and follow their own rituals:** (Neuberger J 1994; Kagawa-Singer M 1998a)

108. **Access to clergy:** (Goldberg R, Guadagnoli E 1990; Cassidy JP, Davies DJ 2004)

109. **Family guidance on wake, memorial service, burial, cremation:** (Weber M, Ochsmann R 1998; Bern-Klug M, Ekerdt DJ 1999; Morgan E 2001; Ellison NM, Ptacek JT 2002; Gatrud R, Sheikh A 2002) {CC 2.6}

Domain 6: Cultural Aspects of Care

110. **Issues of access to end-of-life care within culture and community:** (Gates MF 1991; Todd KH, Samaroo N 1993; Todd KH, Lee T 1994; Phillips RS, Hamel MB 1996; Meier DE, Morrison RS 1997; Chochinov HM, Kristjanson L 1998; Culture Project on Death in America and the Center on Crime and Culture 1999; Haber D 1999; Petrisek AC, Mor V 1999; Reese DJ, Ahern RE 1999; Crawley L, Payne R 2000; Zerzan J, Stearns S 2000; Metzger M, Kaplan KO 2001; Crawley LM, Marshall PA 2002; Dixon S, Fortner J 2002; Flaskerud JH, Lesser J 2002; Gatrud R, Sheikh A 2002; Last Acts 2002; Payne R, Payne TR 2002; Payne SK, Coyne P 2002; Schneider EC, Zaslavsky AM 2002; Allen RS, DeLaine SR 2003; Maddocks I, Rayner RG 2003; Soares LG 2003)

111. **Cultural Assessment:** (Pickett M 1993; Blackhall LJ, Murphy ST 1995; Hallenbeck J, Goldstein MK 1996; Murphy ST, Palmer JM 1996; Bates MS, Rankin-Hill L 1997; Voltz R, Akabayashi A 1997; Bernabei R, Gambassi G 1998; Sagara M, Pickett M 1998; Beutter MB, Davidhizar R 1999; Blackhall LJ, Frank G 1999; Carrillo JE, Green AR 1999; Cykert S, Joines JD 1999; Borum ML, Lynn J 2000; Karim K, Bailey M 2000; Zoucha R 2000; Zoucha R, Husted GL 2000; Christopher M, Emmott H 2001; Gessert CE, Calkins DR 2001; Sahlberg-Blom E, Ternstedt BM 2001; Thomas ND 2001; Vincent JL 2001; Baggs JG 2002; Crawley LM 2002; Crawley LM, Marshall PA 2002; Kobylarz FA, Heath JM 2002) {CCS 6.1; 11.1, 11.2, 12.4; IDT 4.1.9, 5.1, 7.3}

112. **Cultural identification:** (Koenig BA, Gates-Williams J 1995; Noggle BJ 1995; Bates MS, Rankin-Hill L 1997; Brenner PR 1997; Koenig BA 1997; Kagawa-Singer M 1998a; Kagawa-Singer M 1998b; Morrison RS, Zayas LH 1998; Baggs JG 1999; Oncology Nursing Society 1999; Reese DJ, Ahern RE 1999; Taylor A, Box M 1999; Waters CM 2000; Byock I, Norris K 2001; Kagawa-Singer M, Blackhall LJ 2001; McCracken LM, Matthews AK 2001; Berger A, Pereira D 2002; Crawley LM, Marshall PA 2002; Iwashyna TJ, Chang VW 2002) {IDT 4, 4.1.9, 5, 5.1.10, -7, 7.1.3}

113. **Communication within various cultures:** (Koenig BA, Gates-Williams J 1995; Connors RB, Jr., Smith ML 1996; Davis A 1996; Hakim RB, Teno JM 1996; Hallenbeck J, Goldstein MK 1996; Koenig BA 1997; Ersek M, Kagawa-Singer M 1998; Hamel R 1998; Hallenbeck J, Goldstein MK 1999; Moadel A, Morgan C 1999; Dowsett SM, Saul JL 2000; Hopp FP, Duffy SA 2000; Waters CM 2000; Bowman KW, Singer PA 2001; Christopher M, Emmott H 2001; Kagawa-Singer M, Blackhall LJ 2001; Levy MM 2001; Thompson G, McClement S 2002)

114. **Education on cultural diversity:** (Brant J, Ishida D 2000; Ekblad S, Marttila A 2000; Christopher M, Emmott H 2001; Krakauer EL, Crenner C 2002)

115. **Cultural rituals:** (Kagawa-Singer M 1998a;Kagawa-Singer M 1998b;Romanoff BD,Terenzio M 1998;Langford JM 2000;Kagawa-Singer M,Blackhall LJ 2001;Mariano C 2001;Miles SH 2001;Mitty EL 2001) {ARE 2, 2.1, 2.2}

116. **Translation:** (Langford JM 2000;Soloman NRZ 2000;Kagawa-Singer M,Blackhall LJ 2001;Sullivan MC 2001)

117. **Recruitment for diversity:** (Haber D 1999;Karim K, Bailey M 2000;Mechanic D 2002) {HR 8, 8.1, 8.2}

Domain 7: Care of the Imminently Dying Patient

118. **The imminently dying phase is recognized, documented, and communicated:** (Ventafridda V, Ripamonti C 1990;Pickett M,Yancey D 1998;The AM, Hak T 2000;Ellershaw J, Smith C 2001;Kristjanson LJ 2001;Ellershaw J,Ward C 2003;Furst CJ,Doyle D 2004)

119. **End-of-life concerns, hopes and expectations are addressed openly and honestly:** (Neuenschwander H, Bruera E 1997;Lo B, Quill T 1999;Carrese JA, Mullaney JL 2002) {CCS 9, 9.3, 12}

120. **End-of-life concerns are addressed in the context of social and cultural customs:** (Pickett M 1993: National Hospice and Palliative Care Organization 1996;Coyle N, Ingham JM 1999) {CCS 12.3}

121. **End-of-life concerns are addressed in a developmentally appropriate manner:** (Lo B, Quill T 1999;Wolfe J, Grier HE 2000;Wolfe J, Klar N 2000;Perrin KO 2001;Rauch P,Arnold R 2002;Rauch PK, Muriel AC 2002) {CCS 9, 9.3, 12}

122. **Symptoms assessed and treated:** (Hastings Center 1987;Lichter I,Hunt E 1990;Ventafridda V, Ripamonti C 1990;Fainsinger R, Miller MJ 1991;Truog RD, Berde CB 1992;Cherny NI,Portenoy RK 1994;Brody H, Campbell ML 1997;Pickett M,Yancey D 1998;Coyle N, Ingham JM 1999;Du Pen SL, Du Pen AR 1999;Wolfe J, Grier HE 2000;Rousseau P 2002) {See Domains 2 and 3} {CCS 2, 3}

Domain 8: Ethical and Legal Aspects of Care

123. **Interdisciplinary team includes professionals knowledgeable in ethics:** (Council on Ethical and Judicial Affairs AMA 1992;Rushton CH, Hogue EE 1993;Glover JJ,Rushton CH 1995;Quill TE,Cassel CK 1995;Payne K, Taylor RM 1996;Quill TE, Brody H 1996;Bruera E, Selmser P 1997;Post LF,Dubler NN 1997;Scanlon C 1997;Bruera E, Fornells H 1998;Quill TE, Meier DE 1998;Scanlon C 1998;Singer PA,MacDonald N 1998;Council on Ethical and Judicial Affairs AMA 1999;Ziring PR, Brazdziunas D 1999;Csikai EL,Bass K 2000;Meisel A, Snyder L 2000;Zoucha R,Husted GL 2000;Beauchamp TL,Childress JF 2001;Casarett D, Ferrell B 2001;Forde R, Aasland OG 2001;Price KJ,Kish SK 2001;Bascom PB,Tolle SW 2002;Jansen LA,Sulmasy DP 2002a;Kyba FC 2002;O'Keefe ME,Crawford K 2002;Brett AS,Jersild P 2003;Lee S,Kristjanson L 2003;Olthuis G,Dekkers W 2003;Quill TE,Cassel CK 2003)

124. **Assessing decision-making capacity:** (Miles SH, Koepf R 1996;Koenig BA 1997;Hopp FP 2000;Mezey M, Teresi J 2000;Norton SA,Talerico KA 2000;Ganzini L, Volicer L 2003;Volicer L,Ganzini L 2003)

125. **Surrogate decision making:** (Baggs JG 1993;Baggs JG,Schmitt MH 1995;Baggs JG,Schmitt MH 1997;Baggs JG, Schmitt MH 1997;Brody H, Campbell ML 1997;Dowdy MD, Robertson C 1998;Goodlin SJ, Winzelberg GS 1998;Pritchard RS, Fisher ES 1998;Baggs JG, Schmitt MH 1999;Braddock CH, 3rd., Edwards KA 1999;Baggs JG,Mick DJ 2000;Meisel A, Snyder L 2000;Silveira MJ, DiPiero A 2000;Steinhauser KE, Christakis NA 2000;Steinhauser KE, Clipp EC 2000;Teno JM, Fisher E 2000;Zoucha R,Husted GL 2000;Chochinov HM 2002;Chochinov HM, Hack T 2002a;Chochinov HM, Hack T 2002b;Doukas DJ,Hardwig J 2003;Ryndes T,Emanuel L 2003) {ARE 3, 3.5;IDT 11}

126. **Ethical issues in palliative care:** (Blackhall LJ, Murphy ST 1995;Glover JJ,Rushton CH 1995;American College of Physicians--American Society of Internal Medicine End-of-Life Care Consensus Panel 1998;Dowdy MD, Robertson C 1998;Scanlon C 1998;Scanlon C,Rushton CH 1998;Mezey M, Teresi J 2000;Schwartz JK 2001;Stanley KJ,Zoloth-Dorfman L 2001;Boult L, Dentler B 2003;Cantor MD, Braddock CH 2003;Calman K, MacDonald N 2004) {ARE 8, 8.1, 8.2}

127. **Ethics of withholding and withdrawing life-sustaining treatments:** (Cassel CK 1987;Task Force on Ethics of the Society of Critical Care Medicine 1990;Snyder JW,Swartz MS 1993;Block SD,Billings JA 1994;Faber-Langendoen K 1994;Mount BM, Cohen R 1995;Faber-Langendoen K 1996;Faber-Langendoen K, Spomer A 1996;Brody H, Campbell ML 1997;Asch DA, Faber-Langendoen K 1999;Hamel MB, Teno JM 1999;Baggs JG,Mick DJ 2000;Faber-Langendoen K 2000;Phillips RS, Hamel MB 2000;Astrow AB, Puchalski CM 2001;Cist FM, Truog RD 2001;Truog RD, Cist AF 2001;Stroud R 2002;Mueller PS, Hook CC 2003)

128. **Recognizing professional codes of ethics:** (Task Force on Ethics of the Society of Critical Care Medicine 1990; American Nurses Association 1991e; American Geriatrics Society Ethics Committee 1994; American Academy of Neurology Ethics and Humanities Subcommittee 1996; Scanlon C 1996; Wesley CA 1996; American College of Physicians--American Society of Internal Medicine End-of-Life Care Consensus Panel 1998; Cooper MC 1998; American Association of Critical Care Nurses 2001; Casarett D, Ferrell B 2001){IDT 15.1}
129. **Professional specialty groups' code of ethics:** (Baggs JG 1993; Rushton CH, Hogue EE 1993; Faber-Langendoen K 1996; Campbell ML, Frank RR 1997; Prendergast TJ, Luce JM 1997; Loftin LP, Beumer C 1998; Council on Ethical and Judicial Affairs AMA 1999; Schneiderman LJ, Gilmer T 2000; American Academy of Pediatrics 2002; Campbell ML, Guzman JA 2003; Reb AM 2003; Schneiderman LJ, Gilmer T 2003)
130. **Use of artificial nutrition and hydration:** (Billings JA 1985; Fainsinger R, Bruera E 1994; Hodges MO, Tolle SW 1994; McCann RM, Hall WJ 1994; Fainsinger RL, Bruera E 1997; Finucane TE, Christmas C 1999; Teno JM, Mor V 2002)
131. **Palliative sedation:** (Cherny NI, Portenoy RK 1994; Quill TE, Lo B 1997; Burns JP, Mitchell C 2000; Hallenbeck J 2000; Krakauer EL 2000; Krakauer EL, Penson RT 2000; Rousseau P 2000a; Wein S 2000; Loewy EH 2001; National Hospice and Palliative Care Organization 2001b; Rousseau P 2001; Beel A, McClement SE 2002; Cheng C, Roemer-Becuwe C 2002; Cowan JD, Palmer TW 2002; Jackson WC 2002; Jansen LA, Sulmasy DP 2002a; Jansen LA, Sulmasy DP 2002b; Morita T, Hirai K 2002; Quillen T 2002; Rousseau PC 2002; Thorns A 2002; Witte R 2002; Braun TC, Hagen NA 2003; Morita T, Tei Y 2003; Rousseau P 2003; Sykes N, Thorns A 2003)
132. **Referrals to ethics specialists or services:** (Tulsky JA, Lo B 1992; Tulsky JA, Fox E 1996; Dowdy MD, Robertson C 1998; Schneiderman LJ, Gilmer T 2000; Lee S, Kristjanson L 2003; Schneiderman LJ, Gilmer T 2003)
133. **Legal and regulatory issues:** (Swanson JW, McCrary SV 1996; Meisel A, Snyder L 2000; Mezey M, Teresi J 2000; Schlegel KL, Shannon SE 2000; Thorns A, Sykes N 2000; Luce JM, Alpers A 2001; Midwest Bioethics Center 2001; Ramsey G 2001; Roff S 2001; Baluss ME 2002; Kyba FC 2002; O'Keefe ME, Crawford K 2002) {ARE 6.2; CCS 14.1, 14.2}
134. **Death pronouncement:** (Gorman WF 1985; Ferris TG, Hallward JA 1998)
135. **Immediate post-death care:** (Tolle SW, Girard DE 1983; Tolle SW, Elliot DL 1984; Tolle SW, Bascom PB 1986; Romanoff BD, Terenzio M 1998; Weber M, Ochsmann R 1998; Berry P, Griffie J 2001; Block SL 2001; Matzo ML 2001; Morgan E 2001; Ellison NM, Ptacek JT 2002; Gatrads R, Sheikh A 2002; Rawlings D, Glynn T 2002; Warren NA 2002; Walter T 2003) {CCS 15.4; HIFCCS 5, 5.1; HRCFCCS 5, 5.1}
136. **Staff training about death certification and related issues about tissue/organ donation and autopsy:** (Tolle SW, Bennett WM 1987; Kaye NS, Soreff SM 1991; Nearney L 1998; Poole M, Germino B 1998; Romanoff BD, Terenzio M 1998; Weber M, Ochsmann R 1998; Bern-Klug M, Ekerdt DJ 1999; Verble M, Worth J 2000; Block S. D. 2001; Carrese JA, Mullaney JL 2002; Ellison NM, Ptacek JT 2002; Gatrads R, Sheikh A 2002; Hayden G 2002; Kwan C 2002; Rawlings D, Glynn T 2002; Warren NA 2002; Forman WB, Kitzes JA 2003; Pollack CE 2003; Zimmerman S, Sloane PD 2003) {CCS 15.3}
137. **Rights in end-of-life care:** (Meisel A, Snyder L 2000; Ravenscroft AJ, Bell MD 2000; Burt RA 2002; McMillan SC, Weitzner MA 2003)
138. **Physician-assisted suicide:** (American Nurses Association 1991b; Doukas DJ, Waterhouse D 1995; Lee MA, Nelson HD 1996; Tulsky JA, Alpers A 1996; Asch DA, DeKay ML 1997; Suarez-Almazor ME, Belzile M 1997; Quill TE, Meier DE 1998; Emanuel EJ, Fairclough D 2000; Ferrell B, Virani R 2000a; Saunders JM 2000; Tulsky JA, Ciampa R 2000; Saunders JM 2001; Back AL, Starks H 2002; Dickinson GE, Lancaster CJ 2002; Suarez-Almazor ME, Newman C 2002; Werth JL, Jr., Benjamin GA 2002; Meier DE, Emmons CA 2003; Quill TE, Cassel CK 2003)

1 References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

ARE	Access, Rights, Ethics	MI	Management of Information
BCS	Bereavement Care and Services	PI	Performance Improvement and Outcomes Measurement
CC	Coordination and Continuity of Care	SIC	Safety and Infection Control
CCS	Clinical Care and Services	HIF	Hospice Inpatient Facility
HR	Human Resources	NF	Nursing Facility Hospice Care
IDT	Interdisciplinary Team	HRCF	Hospice Residential Care Facility
LG	Leadership and Governance		

