

Domain 5: Spiritual, Religious and Existential Aspects of Care (102, 103)

Guideline 5.1 Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied. (32, 104)

Criteria:

- The interdisciplinary team includes professionals with skill in assessing (14, 104) and responding (105) to the spiritual and existential issues that pediatric and adult patients with life-threatening illnesses and conditions, and their families, are likely to confront.
- Regular, ongoing exploration (104) of spiritual and existential concerns occurs and is documented (including but not limited to life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness and life completion tasks). (39) Whenever possible a standardized instrument should be used. (80)
- A spiritual assessment is utilized to identify religious or spiritual/existential background, preferences, and related beliefs, rituals and practices of the patient and family. (106, 107)
- Periodic reevaluation of the impact of spiritual/existential interventions and patient-family preferences is documented. (36)
- Spiritual/existential care needs, goals and concerns are addressed (8, 103, 104) and documented, and support is offered for issues of life completion (104) in a manner consistent with the individual's and family's cultural and religious values. (106)
- Pastoral care and other palliative care professionals facilitate contacts with spiritual/religious communities, groups or individuals, as desired by the patient and/or family. Patients have access to clergy in their own religious traditions. (107)
- Professional and institutional use of religious symbols is sensitive to cultural and religious diversity. (107)
- The patient and family are encouraged to display their own religious/spiritual symbols. (107)
- The palliative care service facilitates religious or spiritual rituals as desired by patient and family, especially at the time of death. (109)
- Referrals to professionals with specialized knowledge or skills in spiritual and existential issues are made available when appropriate (e.g., to a chaplain familiar with or from the patient's own religious tradition). (37)
- A process for quality improvement is documented and leads to change in clinical practice. (17)

Selected References for Domain 5

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- NOTE: An easy reference to the various sections of the NHPCO Standards of Practice for Hospice Programs (2000) is provided in brackets at the end of each domain.
- NHPCO Standards {HRCFCDCS 2, 5.2; IDT 7, 7.1, 11, 11.1, 11.2}¹

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
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LG	Leadership and Governance		

Domain 6: Cultural Aspects of Care

Guideline 6.1 The palliative care program assesses and attempts to meet the culture-specific needs of the patient and family.

Criteria:

- The cultural background, concerns and needs of the patient and their family are elicited and documented. (110-112)
- Cultural needs identified by team and family are addressed in the interdisciplinary team care plan. (110-112)
- Communication with patient and family is respectful of their cultural preferences regarding disclosure, truth-telling and decision-making. (113, 114)
- The program aims to respect and accommodate the range of language, dietary and ritual practices of patients and their families. (79, 114, 115)
- When possible, the team has access to and utilizes appropriate interpreter services. (116)
- Recruitment and hiring practices strive to reflect the cultural diversity of the community. (117)

Selected References for Domain 6

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- NOTE: An easy reference to the various sections of the NHPCO Standards of Practice for Hospice Programs (2000) is provided in brackets at the end of each domain.
- NHPCO Standards {ARE 2, 2.1, 2.2; CCS 6.1, 11.1, 11.2, 12.4; HR 8, 8.1, 8.2; IDT 4, 4.1.9, 5, 5.1, 5.1.10, 7.1.3, 7.3}¹

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:

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Domain 7: Care of the Imminently Dying Patient

Guideline 7.1 Signs and symptoms of impending death are recognized and communicated, and care appropriate for this phase of illness is provided to patient and family. (118)

Criteria:

- The patient's and family's transition to the actively dying phase is recognized, when possible, and is documented and communicated appropriately to patient, family and staff. (118)
- End-of-life concerns, hopes, fears and expectations are addressed openly and honestly (119) in the context of social and cultural customs (120) in a developmentally appropriate manner. (121)
- Symptoms at the end of life are assessed and documented with appropriate frequency (122) and are treated based on patient-family preferences. (8)
- The care plan is revised to meet the unique needs of the patient and family at this phase of the illness. (36) The need for higher intensity and acuity of care during the active dying phase is met and documented.
- Patient and family wishes regarding care setting for the death are documented. (20) Any inability to meet these needs and preferences is reviewed and addressed by the palliative care team.
- As patients decline, the hospice referral option will be introduced (or reintroduced) for those who have not accessed hospice services. (38)
- The family is educated regarding the signs and symptoms of approaching death (13, 118) in a developmentally-, age-, and culturally-appropriate manner. (119-121)

Selected References for Domain 7

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Ellershaw J and Ward C (2003). Care of the Dying Patient: The Last Hours or Days of Life. *British Medical Journal* 326(7379): 30–34.

Krakauer EL, Penson RT, et al. (2000). Sedation for Intractable Distress of a Dying Patient: Acute Palliative Care and the Principle of Double Effect. *The Oncologist* 5(1): 53–62.

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Rousseau P (2002). Management of Symptoms in the Actively Dying Patient. In: Berger AM, Portenoy RK, Weissman DE, eds. *Principles & Practice of Palliative Care & Supportive Oncology*. Philadelphia: Lippincott Williams & Wilkins, pp. 789–798.

Ventafriida V, Ripamonti C, et al. (1990). Symptom Prevalence and Control During Cancer Patients' Last Days of Life. *Journal of Palliative Care* 6(3): 7–11.

NOTE: An easy reference to the various sections of the NHPCO Standards of Practice for Hospice Programs (2000) is provided in brackets at the end of each domain.

NHPCO Standards {CC 2.6, 3, 3.1, 3.2; CCS 1, 2, 3, 4, 5, 6, 7, 7.1, 7.2, 8, 9, 9.3, 10, 11, 11.1, 1.2, 11.3, 12, 12.1, 12.3, 13, 14, 15, 15.1, 15.315.4; HIFCCS 5, 5.1; HRCFCCS 5, 5.1}¹

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:

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Domain 8: Ethical and Legal Aspects of Care

Guideline 8.1 The patient's goals, preferences and choices are respected within the limits of applicable state and federal law, and form the basis for the plan of care. (8)

Criteria:

- The interdisciplinary team includes professionals with knowledge and skill in ethical, legal and regulatory aspects of medical decision-making. (123)
- The patient or surrogate's expressed wishes, in collaboration with the family and the interdisciplinary team, form the basis for the care plan. (8)
- The adult patient with decisional capacity determines the level of involvement of the family in decision-making and communication about the care plan. (124)
- Evidence of patient preferences for care is routinely sought and documented in the medical record. Failure to honor these preferences is documented and addressed by the team. (8, 34)
- Among minors with decision-making capacity, the child's views and preferences for medical care, including assent for treatment, should be documented and given appropriate weight in decision-making. When the child's wishes differ from those of the adult decision-maker, appropriate professional staff members are available to assist the child. (35, 124)
- The palliative care program promotes advance care planning in order to understand and communicate the patient's or an appropriate surrogate's preferences for care across the health care continuum. (34)
- When patients are unable to communicate, the palliative care program seeks to identify advance care directives, evidence of previously expressed wishes, values and preferences, and the appropriate surrogate decision-makers. The team must advocate the observance of previously expressed wishes of the patient or surrogate when necessary. (8, 34, 125)
- Assistance is provided to surrogate decision-makers on the legal and ethical bases for surrogate decision-making, including honoring the patient's known preferences, substituted judgment and best interest criteria. (8, 9, 125)

Guideline 8.2 The palliative care program is aware of and addresses the complex ethical issues arising in the care of persons with life-threatening debilitating illness. (123, 126)

Criteria:

- Ethical concerns commonly encountered in palliative care are recognized and addressed, using ethical principles to prevent or resolve ethical dilemmas, including: beneficence, respect for persons and self-determination, and associated regulatory requirements for truth-telling, capacity assessment, confidentiality, assent and permission for persons not of legal age to consent, and informed consent; attention to justice and nonmaleficence and associated avoidance of conflicts of interest. (123, 126) The team recognizes the role of cultural variation in the application of professional obligations, including truth-telling, disclosure, decisional authority and decisions to forgo therapy. (See Domain 6: Cultural Considerations). Attention must be paid to the role of children and adolescents in decision-making. (35)
- Care is consistent with the professional codes of ethics, and the scope, standards and code of ethics of palliative care practice are modeled on existing professional codes of ethics for all relevant disciplines. (128, 129)
- The palliative care team aims to prevent, identify and resolve ethical dilemmas related to specific interventions such as withholding or withdrawing treatments (including nutrition and hydration), instituting DNR orders, and the use of sedation in palliative care. (127, 130, 131)
- Ethical issues are documented; (39) referrals are made to ethics consultants or a committee, as appropriate. (132)

Guideline 8.3 The palliative care program is knowledgeable about legal and regulatory aspects of palliative care. (123)

Criteria:

- Palliative care practitioners are knowledgeable about legal and regulatory issues, including federal and state statutes and regulations regarding medical decision-making, advance care planning and directives; (123) the roles and responsibilities of surrogate decision-makers; (124, 125) appropriate prescribing of opioids and other controlled substances; (51) pronouncing death; (134, 135) request for autopsy and organ transplant; (136) and associated documentation in the medical record.
- Patients and families are routinely advised of the need to seek professional advice on creating or updating property wills and guardianship agreements. (133)

Selected References for Domain 8

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- Council on Ethical and Judicial Affairs, American Medical Association (1992). Decisions Near the End of Life. *Journal of the American Medical Association* 267: 2229–2233.
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- NOTE: An easy reference to the various sections of the NHPCO Standards of Practice for Hospice Programs (2000) is provided in brackets at the end of each domain.
- NHPCO Standards {ARE 3, 3.2, 3.3, 3.4, 3.5, 3.6, 6.2, 8, 8.1, 8.2; CCS 14.1, 14.2; IDT 11; 15.1}¹

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CONCLUSION

Palliative care services aim to support patients of all ages with debilitating and life-threatening illness, and their families, through the full course of the illness, regardless of its duration, until cure or until death, and through the bereavement period. Palliative care is delivered through skilled and interdisciplinary attention to pain and other distressing symptoms; emotional, spiritual and practical support; assistance with complex medical decision-making; and coordination across the continuum of health care settings. The goal is to help the patient and family achieve the best possible quality of life in accordance with their values, needs and preferences. These guidelines for quality palliative care programs represent a consensus opinion of the major palliative care organizations and leaders in the United States, and are based both on the available scientific evidence and expert professional opinion.

Clinical practice guidelines such as these have become the accepted means of promoting consistency, comprehensiveness and quality across many domains of health care. The widespread adoption of these guidelines in the United States will help to establish palliative care as an integral component of the health care of persons living with life-threatening and debilitating chronic illness. It is hoped that these Clinical Practice Guidelines for Palliative Care will encourage access to high-quality palliative care that patients and their families can come to expect and rely upon.

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 1991e; 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; HIFSIC 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;Ellershaw 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;Smeenck FW, de Witte LP 2000;Sommer 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,White 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)

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;Coyne 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;Eilershaw 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,Kristjanson 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;Kaysner-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;Kristjanson LJ,Ashcroft T 1994;Kristjanson LJ, Atwood J 1995;1995;Kristjanson LJ, Sloan JA 1996;Hanson LC, Danis M 1997;Kristjanson 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;Brodaty H, Green A 2003;Christakis NA,Iwashyna TJ 2003;Dawson S,Kristjanson 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;Cintrón 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:** (Sansón-Fisher R, Maguire P 1980;Sansón-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;Tulsky JA, Chesney MA 1995;Billings JA,Block S 1997;Bruera E, Selmser 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. R., 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 VN 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;Glance 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;Tulsky 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, Kleeffeld 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;Ventafriida 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 S 2002;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;Savendra 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;Ellershaw 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;Ellershaw 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;Pasacretra J, Minarik P 2001;Breitbart W, Chochinov HM 2004)