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;Piggin 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,Stepp 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;Coyne PJ, Lyne ME 2002;Karasz A, Dyche L 2003;O'Neill J,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;Abrahm 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,Rubenfeld GD 2001;Puntillo KA, Benner P 2001;Rubenfeld 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;Daveson BA,Kennelly J 2000;Nield-Anderson L,Ameling A 2000;Oneschuk D, Hanson J 2000a;Paice JA, Ferrans CE 2000;Paice JA, Ferrons 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;Brodaty 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, Ternestedt 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;Brodaty 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;Zygmont 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, Nikoletti 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;Gatrad 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;Gatrad R,Sheikh A 2002:2002;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, Ternestedt 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, Koepp 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;Gatrad 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;Gatrad 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)

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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		

Appendix 1

Palliative Care and the Hospice Movement in the United States

While new clinical specialties in palliative medicine and nursing are emerging, palliative care has been delivered through hospice programs in the United States for over 30 years. Hospice care is paid for by Medicare and other insurers through a regulated benefit influencing both access to hospice and the types of services that hospices are able to provide. Under current Medicare/Medicaid guidelines, hospice care is covered for beneficiaries of these programs who are certified by their physician as likely to die within six months if the disease follows its usual course, and who are willing to give up insurance coverage for medical treatments of the terminal illness that are focused on cure or on prolongation of life. Many private payers have similar hospice benefits, although these benefits often have day or dollar caps without requirement that coverage of other services be waived. Once the hospice benefit has been accessed, patients and families may receive comprehensive services across all settings of care from an interdisciplinary team, although the great majority of hospice care is delivered at home. Medicare/Medicaid and most commercial insurances pay for medications and equipment related to the terminal illness, as well as practical, psychosocial, respite and bereavement support for caregivers. (1, 4)

As a prelude to understanding the palliative care movement in the United States, it is helpful to recall the context in which the Medicare hospice benefit was enacted in the early 1980s. Post-World War II scientific advances in health care and medical education created an almost exclusive focus on organ systems, disease states and injury-related models of care. Due to technological advances and major public health initiatives during this era, life expectancy grew considerably, and cure became an expectation. The age-old concern for the patient's suffering and the quality of his or her life, a staple of medical practice and the ethos of medicine throughout history, seemed eclipsed by the focus on medical technology. Dying became a medical event, usually in a hospital, and often accompanied by significant pain and isolation.

The hospice movement represented a countercultural phenomenon. In effect, hospice advocates urged the government to give Medicare patients an alternative approach to high-technology, hospital-based medicine, and elect, instead, to pursue a course of palliative care. In retrospect, this forced choice of either curative care or palliative care seems short-sighted. The assumptions that patients with terminal prognoses could be successfully and easily identified and that they, in turn, would wish to use hospice care, were not borne out. Furthermore, advances in costly, and variously effective, interventions that could concurrently ameliorate symptoms, improve quality of life, and potentially increase life expectancy were not foreseen, making the six-month rule and fixed per diem hospice reimbursements appear increasingly arbitrary. (1, 3, 4)

Notwithstanding these insights, the hospices that grew out of the movement of the late 1970s and early 1980s have been successful. Surveys in the United States have consistently demonstrated a high rate of satisfaction with hospice services. (22) The goals of hospice programs are to create increased opportunity for death at home, to focus on the symptom-control and psychological and spiritual issues that are paramount for persons in the terminal phases of an illness, and to provide bereavement support for their families. Since 1974, over 7 million patients and their families have received end-of-life care at home (e.g., a private residence, assisted living facility, group home, homeless shelter) as well as in nursing homes and hospitals through hospice programs, with escalating use in recent years. (1)

The treatment philosophy and primary clinical characteristics of hospice care and palliative care are shared. (5) Both palliative care and hospice programs:

- Acknowledge the patient and their family as the unit of care, and value reduction of caregiver mortality and morbidity by actively reducing the physical and emotional burden associated with caregiving and grief.
- Rely on interdisciplinary assessment, treatment and evaluation.
- Energetically respond to the consequences of illness facing the patient and family, including:
  - Managing symptoms.
  - Providing practical guidance and support of care at home, where most people spend most of their time and most prefer to be as death approaches.
  - Offering anticipatory counseling/crisis prevention/critical decision support.
  - Recognizing the need for health promotion, even in the face of physical decline.
- Address common forms of patient abandonment, such as health care workers' dismissal of patients who "failed therapy," believing "nothing more can be done."
- Incorporate a human development perspective with respect to life-altering illness.

Responding to Community Need

Since the mid-1980s, leading hospices have aimed to expand access to services in order to reach people based on human need, if these individuals did not meet Medicare hospice eligibility requirements or state hospice licensure definitions. Some hospices have contributed to palliative care education through relationships with local universities and colleges in schools of medicine, nursing, pastoral care and social work. Hospice programs that provide services beyond conventional hospice benefits are referred to as "upstream hospice," while those with dedicated professional education, research and public policy/advocacy components are referred to as "comprehensive hospice centers." Some programs have used the term "open access to hospice" to describe their program's absence of proscription on taking all terminally ill patients under care. (3)

In the past eight to ten years, physicians, nurses and other health care professionals in universities and teaching institutions have championed palliative care efforts to improve care for those seriously ill patients who do not meet hospice eligibility criteria or choose not to elect hospice care. These services, while variably defined,

have been collectively termed "palliative care services." They may be independent of hospice services or contractually related to hospices.

Hospices working "upstream" have encountered both financial and regulatory obstacles in their efforts to offer comprehensive services to patients who either do not meet Medicare or other eligibility guidelines or who may benefit from costly therapies that greatly exceed the per diem payment of the Medicare Hospice Benefit. The Medicare requirements governing hospices inhibit treatment of patients with prognoses longer than six months; as a result, hospices have established alternative programs and relationships in order to respond to the palliative care needs of patients who are ineligible for hospice. The continuing debate over whether and how to extend the reach of hospice care (either through the expansion of their duties or the lengthening of the qualifying terminal prognosis) has made it obvious that there is a broader issue than hospice care to be considered.

Hospice care is completely appropriate at the end of life, but palliative care, in one form or another, is indicated, throughout all phases of life, whenever there are significant burdens from illness or trauma. Expanding the reach of hospice care, therefore, is not the answer to the broader need for palliative care. The values that underlie palliative care—namely holistic outlooks, case management and attention to the patient's quality of life and personhood—are values that must be integrated into the health care system of which hospice is already an effective part. (1-4)

Hospice Utilization and Growth

Significant increases both in number of programs and in number of patients served by hospice programs have been documented in recent years. (1) More than 885,000 patients and their families received hospice care in 2002, an increase of nearly 15 percent over the previous year.

Approximately 80 percent of patients who die in the United States experience a variable period of illness and functional decline before death during which they would benefit from palliative care. It is estimated that hospices provide care to 40 percent of adult Americans who experience death with a preceding period of dependency in activities of daily living, and in 2002, 50 percent of U.S. hospice patients had noncancer diagnoses. Currently, more than half of American adult patients who die with a diagnosis of cancer opt for hospice, while in some communities over 90 percent of patients with cancer receive hospice care before death. An additional 2 million caregivers received family/bereavement services from hospice programs in 2002. (1) Due both to regulatory and insurance restrictions to access, and because of the exceptional difficulty of accepting death as a normal process in this patient population, a smaller proportion of pediatric deaths (about 10 percent) are served by hospice. Pediatric hospice programs have grown, especially among larger hospices, in recent years in response to community need. (3)

Bereavement services are a regulatory requirement of certified hospice programs. A recent matched cohort study, employing Medicare claims data of 195,553 elderly spouses of hospice and nonhospice decedents, demonstrated improvement in survival rates for the spouses of hospice decedents, particularly among wives.

The palliative care needs of patients and families across the continuum should be met by a genuine partnership between palliative care and traditional hospice programs. Close coordination and partnerships between palliative care and hospice programs is critical to the support of genuine continuity of palliative care throughout the course of illness and across the continuum of care settings. Palliative care programs will grow to address the needs of patients and families with long and indeterminate life expectancies. Late in the disease course, the complex and intensive terminal care needs of most patients and families facing the end of life are often best met by comprehensive hospice care.

As of 2002, 41 percent of hospices are delivering palliative care services outside the Medicare Hospice Benefit, and another 19 percent are planning such services in order to increase access to palliative care to patients who are ineligible for or unwilling to enter hospice programs. (1) Nearly a third of the nation's 3,200 hospices are hospital-based, and many hospital, nursing home and home-care agency palliative care programs have been both initiated and supported by hospice professionals. Data suggest that palliative care programs in a range of care settings (24) result in marked increases in the number of appropriate and timely referrals to hospice.

As a philosophy of care, the palliative care services and care management offered by hospices should be available to any patient and family who can benefit from them. Access to hospice programs should not be influenced by the availability of life-prolonging therapies or the patient's desire to pursue these approaches, since many, if not most, patients wish to continue life-prolonging treatments as long as the treatment benefits outweigh the burdens. Since these goals are not mutually exclusive, rational policy would support efforts to amend the Medicare/Medicaid "waiver of other services" requirements, and require instead continual reevaluation of cost-beneficial therapies and payment structures.

Finally, while this document has largely focused on the development of guidelines that have a high degree of applicability in institutional settings, additional focused efforts are needed to improve access to hospice and palliative care for Americans in nursing homes, where limited resources, regulatory obstacles and staff turnover often limit the availability of expert interdisciplinary palliative care services. (29-30) Interdisciplinary teams in nursing homes, in partnership with hospitals, hospices and other community resources, must continue to acquire the training and credentialing in palliative care necessary to care for this patient population. The availability of contracts with community hospices is another important, feasible and growing approach to improving access to palliative care services in the nursing home setting.

Palliative Care Services

There is reason to be optimistic about improving access to palliative care services. As of 2002, more than 25 percent of academic medical centers and well over 950 hospitals (about 20 percent of all hospitals in the U.S.) indicate that they provide access to a palliative care program, including hospice. Additionally, nearly a third of the 3,200 U.S. hospices are hospital-based. In the last seven years, more than 1,200 physicians (including 18 pediatricians) have been certified as subspecialists by the American Board of Hospice and Palliative Medicine *(www.abhpm.org)* and approximately 7,000 registered nurses, 43 advanced practice nurses, and nearly 1,000 nursing assistants are certified in palliative care *(www.nbchpn.org)*. Over the last three years, more than 1,000 physicians and 1,500 nurses have attended three-day-long educational conferences sponsored by Education for Physicians in End-of-Life Care *(www.epec.net)* and the adult and pediatric End-of-Life Nursing Education Consortium *(www.aacn.nche.edu/elnec/)*. There are 42 postgraduate medical fellowship programs and two graduate nursing programs in palliative care across the country, and more are in planning stages *(www.aahpm.org)*. In 2003, over 2,300 clinicians attended the NHPCO-HPNA Joint Clinical Conference to advance their skills in hospice and palliative care and more than 1,500 health professionals, representing over 600 hospitals and hospices, attended conferences sponsored by the Center to Advance Palliative Care which were aimed at helping health professionals and managers start and sustain palliative care programs *(www.capc.org)*. Improvements in access to pediatric palliative care have evolved through demonstration models *(www.chionline.org)*, development of pediatric palliative care curricular materials *(www.ippcweb.org and www.nhpco.org)*, as well as increases in federal funding for both pediatric and adult palliative care research. Several programs targeted to nursing home professionals have also been developed *(www.capc.org/specialpopulations)*. (30) Educational initiatives in social work include several fellowship training programs and Web-based curricula *(www.swlda.org)* and *(www2.soros.org/death/swlda)*. (28)

History of the National Consensus Project

Development of U.S. palliative care consensus guidelines was discussed during a national leadership conference coordinated by the Center to Advance Palliative Care *(www.capc.org)* that was held in December 2001 at the New York Academy of Medicine. Participants at this conference (listed at *www.nationalconsensusproject.org*) were identified through a national peer nomination process. The early goals of the National Consensus Project were:

1. To define an effective national consensus process for establishment of clinical practice guidelines for quality palliative care in the United States.

2. To develop such guidelines through an evidence-based iterative review process that involved the major palliative care organizations in the United States and a large number of professionals in diverse disciplines.

3. To disseminate these guidelines to all stakeholders involved in the delivery of health care to persons with life-threatening illnesses in the United States.

A time line detailing the activities of the National Consensus Project between December 2001 and the publication of these guidelines may be found at *www.nationalconsensusproject.org.*

Organizational Structure of the National Consensus Project

The National Consensus Project has been structured to maximize the participation and input of a broad range of palliative care professionals, health care organizations, policy and standard-setting bodies, consumers and payers. To this end, a series of working groups has been formed to ensure a comprehensive, transparent and representative consensus process underpinning the development of Clinical Practice Guidelines for Palliative Care.

Consortium Organizations for the NCP: Based on recommendations from the broader palliative care community, five key national palliative care organizations formed a consortium to oversee and ensure the success of the National Consensus Project. The consortium includes:

- **American Academy of Hospice and Palliative Medicine:** A physician membership organization for palliative care and hospice professionals. (*www.aahpm.org*)
- **Center to Advance Palliative Care:** A Robert Wood Johnson Foundation–funded initiative to promote the development of quality palliative care programs in hospitals and other health care settings. (*www.capc.org*)
- **Hospice and Palliative Nurses Association:** A nursing membership organization for palliative care and hospice professionals. (*www.hpna.org*)
- **Last Acts Partnership:** A national, not-for-profit organization dedicated to improving care and caring near the end of life by informing health care professionals, advocating for policy change, and empowering private citizens with information and opportunities for action. (*www.lastactspartnership.org*)
- **National Hospice and Palliative Care Organization:** A hospice and palliative care advocacy and provider membership organization serving U.S. hospices, palliative care members and their professional staffs. (*www.nhpco.org*)

Steering Committee: Each of the five consortium organizations has appointed four representatives to a Steering Committee (members are listed on page vi). The Steering Committee was charged with the writing and timely completion of the consensus document, communication and dissemination of progress reports to all appropriate NCP participants, and procurement of the necessary financial support for the project. The committee made all decisions regarding the NCP through a voting process at its regular monthly meetings.

Advisory Committee: An Advisory Committee (members are listed in Appendix 2) was established concurrently with the Steering Committee. This group, which includes 96 nationally recognized palliative care leaders nominated by their peers, served as document reviewers and key contributors to document development and revision.

Liaison Organizations: During the process of document creation, a list of liaison organizations was developed. More than 100 organizations with major responsibility for the health care of patients with life-threatening illnesses in the U.S. were asked to offer their endorsement and to assist in the broadest possible national dissemination of the standards.

Process for Developing Consensus

The Steering Committee developed a process for drafting and reviewing the document. The steps in this process are as follows:

- The Steering Committee developed an outline that identified the key domains after review of all existing standards and consensus documents (31) and input from the Advisory Committee.
- Clinical practice guidelines were developed based on consensus and the best available scientific evidence.
- Drafts of the document were reviewed and edited by the Steering Committee. Using a 1–4 scale, the committee reviewed and rated each section/item. A score of 1 was a full rejection; 2 was a rejection with multiple reservations; 3 indicated acceptance with reservations; and 4 indicated full acceptance of the section/item.
- The Steering Committee reviewed and discussed the tally of the ratings and comments, and through discussion resolved or revised any item receiving less than 70 percent agreement.
- The revised document was reviewed by the Steering Committee. When more than 70 percent of committee members voted to accept the document, it was distributed to the Advisory Committee for review and rating using the 1-4 scale, and to the five consortium organizations for review by their boards of directors or respective governing bodies.
- Feedback and ratings by the Advisory Committee and consortium organizations were tallied and reviewed by the Steering Committee. Subsequent revisions were reviewed, voted on and approved by the Steering Committee. Unanimity of approval by the boards of all five consortium organizations was required at this stage of document development.
- The document was then distributed to all the liaison organizations for endorsement and assistance in national dissemination of the guidelines.
- In order to ensure the success and effectiveness of the project in improving access to quality palliative care in the United States, a comprehensive communication and dissemination plan for the document was developed. The plan is intended to ensure distribution of the guidelines to organizations, associations, clinicians, managers, providers, policy-makers, educators, researchers and other individuals who plan, provide or assess palliative care programs.

Appendix 2

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