INDEX

Abramson, J. S., 165
Acute stress disorder, 376–77
Adams, P., 856, 865–66
Addictions, 469–73, 567, 718
Adjustment disorder, 368–69
Advance directives: conflicts between wishes of patient and family, 270; in context of long-term care, 632; cultural differences in use of, 455; discussions of, opportunities, unwillingness, 765–77; education issues, 552–53, 771–75; failures to accompany patient to hospital, 635; family’s or physician’s unwillingness to comply with, 156, 764; federal and state policies, 762–63; forwarded by Cruzan case, 761; for gays and lesbians, 493; healthcare proxies and proxy directives, 597, 598, 635, 688–89, 733–34, 764; immunity for healthcare providers complying with, 176; inclusive, 603; information as part of nursing home admission process, 632; inmates’ lack of understanding of, 610; legal issue of enforcement, 739; living wills, 156, 635, 733–34, 762–63; Medicare requiring query as to, 762–63; need arising along with medical advances, 761; need for separate directives for different states, 763; for nursing home patients, 629; for prisoners, 784; purposes, types, characteristics, difficulties, and benefits of, 175–76, 732–34, 762–64, 765–67, 771–72; recommendations by AMA, 764–65, 766–67; stating patient’s preference, 773; transplant patient (with case example), 688–89; values history as adjunct to, 735, 742, 766
Advance directives, legal issues: Bergman v. Eden Medical Center, 749; constitutionality of state statutes, 738–39; enforcement, 739; improving due process guarantees for incompetent patients, 740–41, 748; injury from unwanted treatment as “battery,” 739; new generation of, 741–42; protection for doctors for double-effect euthanasia (pain relief hastening death), 739–40
Advance directives, problems with: absence of legal liability for noncompliance, 734, 735; ambiguity as to ability to refuse “hydration and nutrition,” 734–35; ambiguity as to “terminal illness or condition,” 743; factors behind nonuse by most Americans, 737; failure to address unpredictability or ambivalence of patient at end of life, 742; fear of litigation, 737; ideological influences of right-to-life principle, 744; ignorance, conflict, or value-substitution on part of healthcare proxy/surrogate, 735; incorrect belief regarding refusal or termination of life-support measures, 735; legal presumption in favor of treatment, 737; opposition to, by “state interests,” 735–37; physicians or healthcare institutions unduly influencing patient’s decision making, 741; polarizing clash of legal versus medical paradigms, 737–38; requirement of “clear and convincing evidence” to refuse life support, 735; restrictive state statutes, 734; unconstitutional restriction of autonomy, prolonging suffering, 735
Adventure-based experiential practice, 651–53, 658
African Americans: advance directives, lower prevalence of, 604–5, 774; disparities in quality of health care, 444–45; disproportionate numbers incarcerated, 611; expressions of bereavement/grief/mourning, 258; impeded access to hospice care, 445; impeded access to routine primary care, 715; percent under hospice care, 417;
African Americans (Cont.)
population projections, 440, 441; vulnerability to undertreatment for pain, 383, 718; see also Discrimination; Multicultural issues
Ageism, personal, cultural, and structural, 348–58
Aging baby-boomer generation, 43–54
AIDS. See HIV-affected patients and families
Air hunger (panic attacks), 703
ALS, living and dying from, 43–54
Aliilio, T., 380–406, 549, 559, 560, 566, 834
Alzheimer’s dementia, 366–67
American Indians: population estimates, 441; spiritual involvement with dead, 258, 259; see also Multicultural issues
Anam cara (soul friend), 860–61
Anastas, J. W., 483
AND (Allow Natural Death) orders, 358
Anemia, 367
Anger and hostility, 282, 283–84, 299–300, 646–47, 715–16
Annas, G. J., 598
Anticipatory grief, 254, 303, 324–26, 646
Antigone, 139
Antonovsky, A., 573
Anxiety, 282, 374–77, 394, 555–59, 703, 836
AOSW (Association of Oncology Social Work), 179, 835
Appleby, G. A., 483
Argentine “Dirty War,” 670–71
Ariès, P., 130–31, 139
Aries, H. R., 795
Armenia, earthquake, 672
Aromatherapy, 500
Aronson, L., 660–73
Arons, S., 730–54
Art therapy, 500, 651
Ashcroft, J., 748
Asians: collectivist approach to decision making, 601–3; 604, 605; expressions of grief, 258; population projections, 440, 441; prohibited discussion of terminal diagnosis, 365, 773; see also Multicultural issues
Assessment, clinical: cross-cultural, 450–52; importance of “stories” in, 120–21; pain and symptom management, 344–15, 391–97; patient-centered interviewing, 222; spirituality and religion, 104–95, 196–98, 428–34; treatment issues, 282–83; see also Coping and coping styles; Depression; Family assessment; Mental health risk in end-of-life care; Pain and symptom management; Values and attitudes
Assessment, of larger contexts and institutions: expansion of knowledge base, 728; facets for investigation, 727; financial issues, 727–28; legal issues, 730–32; national priorities and policies, 727; paucity of social work research and documenta-
tion, 728; social work program development, 728; see also Research in social work conceptual frameworks
Association of Oncology Social Work (AOSW), 179, 835
Atrocities, 32–33; see also Disasters and sudden traumas
Atig, T., 226, 236
Audiotapes, 403, 712
Autonomy: advance directives unconstitutionally restricting, 735; as authenticity and acting “in character,” 603–6; balancing with moral rights of care providers, 180–81; as bioethical principle, 174; cultural attitudes, 773–74; debate over physician-assisted suicide, 752–53; and decisional capacity for disabled persons, 503–4; definition of, 594; depression weakening patient’s claim to, 737; ethical issues of mental condition (case example), 594–97, 599; as free action, without undue influence, 605; informed consent and refusal of medical treatment, 179, 732–33; informed consent and self-determination (with case example), 594–97, 599; informed consent and truth telling, 594, 596, 598; interdisciplinary teams’ acceptance of decisions divergent from own beliefs, 718; as participation in interdependent relationships, 231; and Patient Self-Determination Act, 407, 476, 603–6, 632, 633, 733–34, 761, 762; of patient versus physician’s paternalism, 171; social workers’ allegiance to self-determination, 184; versus decision making as family or in communal process, 388, 465, 466; without undue influence or interference, 179; see also Advance directives; Self-determination
Autopsies, 330
Awareness, suggested questions to explore patient/caregivers perspectives, 123–24

Baby-boomer generation, xix, 409, 838–39
Beltran, J. E., 507
Beneficence as bioethical principle, 174, 182, 388, 594
Bennett, A., 786
Benolie, J. Q., 138
Benson, H., 400–401
Bereaved, helping the: by “casserole brigade,” 578; children grieving, 577, 585–86, 588; by clergy and funeral directors, 62–63, 193, 572, 578–79; cognitive behavior therapy, 588; cultural factors in mourning behaviors, 577; determining extent of change, 574–75; disenfranchised grief in nursing homes, 677–78; disenfranchised grief in prisons, 787; disenfranchised grief in schools, 578; families in early stages of mourning, 576–77; families of transplant patients, 690–91; families, programs for, 568, 587–88; healthcare professionals, 579; hospice bereavement programs, 579–80; lack of, and need for, insurance coverage for, 822; many needs, many forms of help, 571–72; mental health risk factors related to bereavement, 580; mutual-aid and self-help programs, 585–83; National Center for Grieving Children and Families, 586; needed help changing with time, 576–78; network of mutual-aid organizations, 145; openness to help, 573; Pathfinders self-care program, 585; peer support, 220; responding to stage of grieving process, 572; social support, 575–76; social workers as counselors, xxiv; sources of help, 572–73; 578–79; staff members of transplant teams, 691; stories as narrative therapy, 587; support groups, 588–89, 580–81, 587–85; victims of disasters and sudden trauma, 668–73; Widowed Persons Service (AARP), 145, 583

Bereavement/grief/mourning, characteristics: ambiguous loss, 49; as annihilation anxiety with feelings of persecution, 249; anticipatory grief, 254, 303, 324–26, 646; comparison of terms, 226; complicated mourning, 218–19, 670; constructivist views, 255–57; cultural variations in rituals and expressions of, 208, 257–59, 372–73; culture-based, historical, changing views of, 138–40; decision making, difficulty of, 49; as detaching from and letting go of relationship, 141, 142, 143–44, 235, 247; detachment and dissociation in grief, 143–44, 244, 253; developmental context, 228–32; differing experiences of loss, 351; disenfranchised grief, 549, 494, 492–93, 574, 787; 857–58; dual process theory, oscillation, 352–53; as flight into manic activity and dependency avoidance (with case example), 248; Freud’s theory of, 243; gender-related interpretation of behaviors, 211–13; guilt, 141; as illness, 144–45; for inmates, ubiquitous and familiar, 618–19; meaning as contextual, 128–29; melancholia (with case example), 244–45, 246–47; mental health risk in, 372–74; minimization of ritual, emotion, sanitization of mourning, 140, 253–54; object relations in, 248–54; pathological or chronic, 140, 142, 253, 255, 257; as potential area of research, 810; relational context, 146, 220, 227–28; risk of death following, 212; searching mode, suspended grief process, 670; shifts in theory of, 214–15; social workers grieving over death of patients, 317; stages of, 253; studies of grieving children, 141–42; twentieth-century context, 140–43

Bereavement/grief/mourning, as transition and transformation: attachment styles, 254; as building new “normality,” 351; connecting to, continuing relationship with deceased, 255, 247; empowerment evolving from, 232; expansion of ego ideals (with case example), 247–48; initial responses, 237–38; learning, creating, developing, 574–75; loss- and restoration-oriented responses, 238; maintenance of inner representation as link to loved one, 231; as meaning making, 193, 256, 351, 353; as negative but adaptive emotion, 242–43; as nonstatic process with change over time, 231, 236–39; as normal, expected period of transition, 144, 226; periods of dynamic instability, 232; recoil into new reality, feeling fullness of loss, 238; “stories” as adaptations to loss, 13; transcendence, transformation, and transition, 31–32, 101, 143, 232–33, 256, 260; without “recovery” but with accommodation and change, 227, 238–39, 373; “work” and “tasks” of transition, 236; see also Stories
Berger, T., 786
Bern-Klug, M., 628–40, 792–812
Bioethics, 172–73; see also Ethical issues
Biofeedback, 702
Biopsychosocial services, 313–14
Bipolar disorders, 370
Birkett, D.P., 635
Blacker, S., 409–22, 548–69
Blacks. See African Americans
Blame, 284
Blickensderfer, L., 167
BMT (bone marrow transplantation). See Transplantation
Boccuti, C., 815
Body/organ donor programs, 633
Bone marrow transplantation (BMT). See Transplantation
Boss, P., 49
Boston’s Coconut Grove nightclub fire, 254
Botes, A., 164, 165
Bowlby, J., 141–42, 143, 252–54
Bowman, T., 197, 853
Brenner, P. R., 445
Brody, H., 29–30
Browning, D., 21–41, 70
Brumley, R., 822–23
Buber, M., 29, 37, 860
Buddhist perspective on suffering, 24
Bulletin board groups, 542; see also Groups, online
Burger, S. G., 634
Burial rituals, 192
Burnette, D., 800
Burnout, xxvi, 83, 849–52, 853
Burton, S., 166–67
Burt, R., 753
Byock, Ira, 27, 102, 137, 418, 477, 816, 821
Cabot, R., 826
Cady, N., 166–67
Callahan, J., 172
Camp programs for terminally ill children, 336, 337
Canadian Hospice Palliative Care Association (CHPCA), 411, 412
Cancer: as catalyst for positive transformation, 707; cognitive therapy, 702; as deadly intruder, 696; decision to join clinical trial, 706; declining mortality rate, 697–98; diagnosing, 699; diagnosis precipitating crisis of self-concept, 701–2; disproportionate weight on test results, 707; educating patients and caregivers, 702; effect of patient attitude, 707; emotional support for patient and caregivers, 704–5; fear of inferior treatment, 710, 714–15; localized versus metastatic, 698–99; pace of diagnostic process, 696; pain and symptom management, 709; patient’s reluctance to take up doctor’s time, 708; patient’s reticence and sense of isolation, 696; phase one, diagnosis, 700–705; phase two, treatment, 705–7; phase three, terminal care, 707–11; relationships with cancer-care specialists, 705; social worker’s role during treatment, 706–7; social worker’s role following diagnosis, 701–5; social worker’s role in end-of-life care (with case example), 697, 709–10; social worker’s role in terminal care (with case example), 708–11; suicidality, 704; support groups, 705; treatments, 699–700; type versus location in body, 699; unpredictability for patients and families, 697–98; urgency of decision making on treatment, 706; varying types and courses of disease, 697–700
Cancer Care (social work agency), 834, 835
Cassell, E. J., xxvi
“Casserole brigade,” 578
Cassidy, J., 380
Cemeteries. See Graves, grave-markers, tombstones
Cemeteries, 131–32
Chachkes, E., 825–36
Chantler, C., 163
“Chaos stories,” 51
Charitable organizations. See Professional organizations and foundations
Chat groups, 542; see also Groups, online
Chemomas, W. M., 436
Children: development of, 229–30; development of institutionalized and abandoned, 252–53; development through internalizations, 250, 251; in disasters and sudden traumas, 666–73
Children at end of life, issues for parents: allowing for range of feelings and for spiritual growth, 327–28; anticipating funeral preparations, 318, 329; autopsies, 330; coping with helpless-
Children at end of life, working with: acknowledging loss, clarifying reality, adolescents, 341; belief reflecting those of parents, 331; children protective of parents, 337; child’s own wishes regarding DNR orders, 324; conceptions of death and developmental considerations, 338–41; continued development, 322–33; death anxiety, 342; desire to be remembered, to live on in some way, 344–45; event-based focus, 331; fears of having done something wrong, 340; fears of threats to body integrity and function, 340; group work, 335; guilt about dying, 329; helping live life to fullest, 330; honesty in age-appropriate manner, 330–31; life review and preview, 333–34; memorial balloon launch, 337; need for honest communication, 319–20; need for models of pediatric palliative care, 417; play and art therapy, 321–22; recognition for accomplishments, 331; requesting advice on care of child with similar illness, 333; social workers’ reactions to the work, 334–42; social workers sharing journey and meaning of life, 344–45; talking about death, 335–36; understanding of their illness and death, 319–20; use of metaphor for death, 326, 337.

Children, facing death of loved one: addressing fears, 313–14; centers for, 313–18; chance to say goodbye, 322; constructing relationship to deceased, 325–30; “desertion” by parents during illness of sibling, 322, 338; explanations by parents, 577; explanatory styles affecting behavior, 588; for gay/lesbian parents, 493–94; grieving by, 230, 237; guardianship issues (with case example), 712, 713; internal representations of deceased, 256; parent undergoing transplantation (with case example), 683–84, 686; reactions to loss, 248–49; recognition of loss by teachers, staff, fellow students, 578; studies of grief in, 337–38.

Chirban, J. T., 434–35
Chodron, P., 24, 34
Christ, G. H., xix, 549, 559, 561, 566, 834, 835
Christianity: attitudes toward death, 131–32; perspective on suffering, 24–25
Chronic illness, 8, 171, 286, 410, 773, 815, 839
Cincotta, N., 318–45
CISD (Critical Incident Debriefing) sessions, 85–86
Clark, E. J., 835–46

Clergy, 62–63, 193, 572, 578–79
Client Self-Determination in End-of-Life Decisions policy statement, xix–xx, 175–79, 770
Clinchy, B., 36
Clinical ethics, 388
Clinical practice: absorbing and tolerating individual’s or family’s anger, 720; biopsychosocial services, 313–14; catastrophic illness, 54–55; collaboration and referrals, 270; counselor, choices, and decision making, 302–3; counseling, 313; difficulty of therapeutic relationship with inmate, 609; dignity in death, affording to patient, 301–3; dread of death, helping patient deal with, 298–301; education of staff, 315; essential skills overview, 265–67; families, staving off dissonance, 296; final wishes, definition and expression of, 296; gay and lesbians, guidelines for working with, 492–94; with groups, 270, 335, 529, 531–32; with groups, 270, 539–40, 545; with groups, online and telephone, 520–31, 534–45, 621–32; holding environment, developing, 310–12; holistic, 431–32; hope and reality, denial of death, 309; hope in social work clinician, 309–10; hope, role in dying process, 304–7; hope, role in interdisciplinary team, 307–9; insufficient improvements in, 8; intercession for pain relief, 296; interdisciplinary collaboration, 314–15; key interventions, 276; marginalized dying and bereaved, 474–75; need for role flexibility, 279; objectivity, problems of, 272; offering respectful death, 265; older people, implications of work with, 356–57; pain, “permission” for acknowledgement of, 296;
Clinical practice (Cont.)
palliative care for disabled persons, 506; in prison settings, 615–16; research areas, 803; resistance to treatment, 281; role changes within families, 303; self-knowledge, 266–67; serving as anxiety-containment vessel, 282; sexuality, 303; social work action plan, 844; staying connected while maintaining perspective, 266; supervision, 315–17; treatment process, expectations and anxieties, 281–83; working with “open heart,” 267; see also Cancer; Children; Family assessment; Family Unity (retreat program); Mental health; Older people; Pain and symptom management; Palliative care; Skills of social workers; Support groups; Transplantation and end of life CoCoanut Grove (Boston) nightclub fire, 254 Coddou, F., 162 Coffey, E. P., 43–54 Collaboration. See Interdisciplinary teams Colón, Y., 482–95, 534–45 Commitment to therapeutic relationship, 110, 111 Communication: avoiding thoughtless use of language or jargon, 717; cross-cultural, 454–56; in families, patterns and styles, 551–53; father’s unwillingness to discuss diagnosis with son (case example), 562; issues at end of life, 508; patients’ difficulties speaking with loved ones about their condition, 510, 516; as potential area of research, 807; see also Truth telling Community, sense of: experiential activities at Family Unity (retreat program), 650–53, 658, 665; family within prisons, 785, 786, 788–89; mediating isolation of bereaved, 581; in nursing homes, 637–38; through support groups, 583 Compassionate Friends (support groups), 445, 582 Compassion fatigue, 477, 852–53 Compassion for suffering, 34–36 Compassion in Dying organization, 745, 768 Compassion in Dying v. Washington, 745 Complicated mourning, 218–19, 670 Confidentiality and privacy issues, xxiv, 61, 521 Connection to patient, 110–11, 320–21 Controlled Substances Act (CSA), 382 Control, patient’s sense of, 285–87, 302–3 Cooke, R., 65 Cook, J. A., 216 Coping and coping styles: as adaptive behavior, 575; assessment of possible impact of bad news, 305; assessment of possible mental health risk, 363–65; effect of previous experiences with illness, disability, or death, 577–78; enhancing with internal or spoken statements, 400, 568; gender-based variations, 212, 246; multicultural issues, 613; suggested questions to explore patient/caregivers perspectives, 124; through promoting, validating, and normalizing range of emotions, 717; uniqueness in face of emotional and practical havoc, 716 Conless, I. B., 166–69 Costs of care. See Financial issues Counseling, 313, 561–62, 587–88 Countertransference: engaging multiple subjectivities, 272; example of, 854; inappropriate neutrality and boundaries, 70; interfering with case, 435–36; need to address in supervision, 315–16; possible challenge to basic beliefs, 191; potential for, with terminal cancer patients, 709; stress affecting ability to manage, 88; therapist’s grappling with, 434–36; upon patient’s refusal of pain medications, 709; vicarious traumatization, 853–54; in work with gays and lesbians, 492 Critical Incident Debriefing (CISD) sessions, 85–86 Cross, T., 443 Cruzan v. Harmon and Cruzan v. Director, Missouri Dept. of Health, 135, 732, 734, 747–44, 745, 748–49, 75913, 75912, 759123, 759043, 763 Csikai, E., 701–75 Culture, 554; see also Multicultural issues Cummings, I., 468, 411, 412 Curanderos (case example), 439, 453–54, 458–59 Curing, 164 Damaskos, P., 72–91 Dane, B., 444–57, 835 Daughters: middle-aged, experiencing loss of parent, 206; serving with power of attorney for healthcare for parents, 217–18; see also Gender issues Davidson, K., 835 Davie, K. A., 835 Dawes, D., 778 Dawes, J., 778 DEA (Drug Enforcement Agency), 382 Death anxiety, 213, 249, 258–301, 342 Debriefing, Critical Incident Debriefing (CISD) sessions, 85–86 Decision making: allowed to patients, 302–3; autonomous versus shared or family-based, 465, 465, 601; “best interest” judgment, 467, 504; capacity compared to legal “competence,” 465, 503; decisional capacity (with case example), 597–601;
Index 877
difficulty when frozen with grief, 49; diminished
capacity, marginalization of those with, 465–68; ethical,
models of, 173–74; physicians or healthcare institu-
tions unduly influencing, 742; power of attorney for
healthcare, 176, 635, 733; as rushed process in cases of
catastrophic illness, 48–49, 57; “substituted” judgment,
467, 504, 597, 733, 764; surrogate decision makers,
175, 179, 406, 524–55, 552, 563, 735, 740–41, 764
Del Rio, N., 439–59
decision-making capacity, 269; as essential role
process, 228–31
Denial, 559, 598
dementia or delirium, 366,
Del Rio, N., 439–59
decision-making capacity, 269; as essential role
process, 228–31
Denial, 559, 598
dementia or delirium, 366,
Del Rio, N., 439–59
decision-making capacity, 269; as essential role
process, 228–31
Denial, 559, 598
dementia or delirium, 366,
Del Rio, N., 439–59
decision-making capacity, 269; as essential role
process, 228–31
Denial, 559, 598
dementia or delirium, 366,
Del Rio, N., 439–59
decision-making capacity, 269; as essential role
process, 228–31
Denial, 559, 598
dementia or delirium, 366,
Del Rio, N., 439–59
decision-making capacity, 269; as essential role
process, 228–31
Denial, 559, 598
dementia or delirium, 366,
Del Rio, N., 439–59
decision-making capacity, 269; as essential role
process, 228–31
Denial, 559, 598
dementia or delirium, 366,
Del Rio, N., 439–59
decision-making capacity, 269; as essential role
process, 228–31
Denial, 559, 598
dementia or delirium, 366,
DNR orders (Cont.)
in pediatrics, 323–24; in
prisons, 784; research
needed into timing and
decision making, 475
Dobson, M., 144
Doka, K., 67, 69, 70, 211, 425,
857
Dombeck, M., 196–98
Donor programs, 633
"Do Not Hospitalize" orders,
635
Double effect, principle of, in
pain management, 388–89,
739, 750
Double H Ranch Hole in the
Woods Camp, 648
Dougy Center, Oregon, 586
DSM IV (Diagnostic and
Statistical Manual of Mental
Disorders, 4th ed.), Multiaxial
Assessment, 362, 366, 665
Dual process theory, oscillation,
352–53
Due process protections,
740–41, 748
Durable power of attorney for
healthcare, 176, 217–18, 635,
733; see also
Advance
directives
Dying and death: as catalyst for
life review, 597–94;
conscious, 55; as control-
able, avoidable obstacle to
be overcome, 135, 172;
delaying by modern tech-
nology, 135–36, 152, 176–77,
217, 302–3, 409, 410, 464,
598, 611, 725, 737, 753, 760,
815–16, 823; denial by
medical culture, 133; as
developmental stage of
human life cycle, 27; diffi-
culty of accurate prognosis,
108, difficulty of defining,
conceptual ambiguity of,
794–95, as "failure of medi-
cine," 100, 102, 133, 477; fear
of death and/or afterlife, 282,
298; as focus of legal inter-
ventions, 73; as frequent
and familiar visitor, 130–33;
imminence as diminishment
of self, 133–34, 484; limits of
science, 135–36; meaning as
contextual, 128–29; meaning
making as central in, 31, 172;
as merciful release or being
robbed of unlived life, 351; as
metaphor for, use with chil-
dren, 326, 337; in prison,
609; as reminder of impor-
tance of living authentically,
478; as remote and immi-
nent, 132; stages and possible
courses of expectation,
483–84; as tame, 131; top
causes of, 411; views in
Victorian times, 132–33;
where death occurs, 410–11;
see also Social workers,
facing own mortality
Earthquakes, Turkey, India, and
Armenia, 662–63, 672
Education for Physicians in
End of Life Care (EPEC),
172, 477, 547, 767
Education issues: advance
directives, 774–75; cultural
and ethnic differences, 842;
effort required by PSDA
(Patient Self-Determination
Act), 762, 771; foreign
language versions of educa-
tional materials, 476; gender-
related implications, 221;
hospice care, 159; interdisci-
plinary teams, 167; managed
care threat to existing model
of social work education,
840; marginalization of the
dying and bereaved, 474;
older people, 355–56; pain
management and coping,
397–98; palliative care, 420,
422; palliative care access for
disabled persons, 506; as part
of social workers’ self-care,
862; physicians, 819; social
work action plan for, 844;
staff, 315; social work in end-of-life
care, 858; support for, 828
Egnew, T. R., xix–xxvi,
102–25
Ego in mourning, 247
Elderly. See
Older people
Elijah the prophet ("wounded
healer" story), 34–35
Ellis, K., 628–40
ELNEC (End of Life Nursing
Education Consortium),
547
Email groups, 542; see also
Groups, online
Emergency rooms of hospitals,
816
Empathy: as caring manner,
164; in palliative care, 36–37;
requiring supervision and
training, 310
Enders, S., 609–26
End of life: definition of, 108;
difficulty of defining,
conceptual ambiguity,
794–95
End-of-life care: for aging U.S.
population, xix, 409, 838–39;
Americans increasingly artic-
ulating desires for, 157, 410;
challenges related to
managed care, 840; choices
limited by nature of health-
care reimbursement, 815;
core competencies defined,
843; dying alone as antithesis
of good care, 782; few hospit-
tals offering, 7; focus ques-
tions for contributors to this
book, 7; improvement,
growing awareness of need
for, 136–37; improvement;
recognition of need for, 815;
requisite repertoire of
social work modalities, 827;
role of law as pervasive,
730, 753; as term of recent origin,
815; treatments prolonging
life, 152, 172, 176–77, 217,
302–3, 409, 410, 464, 598,
611, 725, 737, 753, 761,
815–16, 823; treatments
requiring full repertoire of
social work modalities, 827;
role of law as pervasive,
730, 753; as term of recent origin,
815; treatments prolonging
life, 152, 172, 176–77, 217,
302–3, 409, 410, 464, 598,
611, 725, 737, 753, 761,
815–16, 823; treatments
continuing process, 172;
trends, influences, and issues
Ethical issues: artificial life supports, suicide, and euthanasia, 32, 115–36, 171, 175–77, 217, 577; balance of, 171; bioethical principles and associated obligations, 174, 392, 394–97; clinical ethics, 388; critical social-work skills, 183; decisional capacity of patient, surrogate decision maker, 175, 176, 465, 733; decisional capacity (with case example), 597–601; definitions, 593; dilemmas of medicalized versus patient-centered care, 502; disclosure to patient of seriousness of condition, 172; early policy effort on stopping unwanted treatment, 516–17; gender in moral dilemmas and decision making, 275–78; good compared to “right,” 593; justice versus care when perspectives differ, 164–65; 594; online resources, 547; medical futility, 179–83, 508–9, 599–603; medical prolongation of life at cost of quality of life, 152, 176–77, 217, 302–3, 409, 410, 464, 598, 614, 725, 737, 753, 760, 815–16, 825; models of ethical decision making, 173–74; need for practical steps, six–xx; pain and symptom management, 387–91; physician-assisted suicide, 177–79; as potential area of research, 811; prevention, 582; public guardians of disabled persons, 505–6; recommendations for social work, 183–84; role of culture (with case example), 601–3, 604, 605; social work perspective contributing leadership, 833; suitability of social workers for involvement in, 172; surrogate decision makers, 175, 176, 465, 504–5, 552, 563, 733, 740–41, 764; technology transforming catastrophic illness into chronic illness, 8, 171, 286, 410, 773, 815, 839; underdeveloped research areas, 820–23; see also Advance directives; Autonomy; Euthanasia; Values and attitudes

Ethnography: description and advantages of, 22–23; guidelines, 28–29; of professional caregiving, 27–29; of suffering, 23–27; see also Stories, as meaning, contiguity, sense of identity

Euthanasia: compared to double-effect intervention for pain relief, 388–89; compared to physician-assisted suicide, 177, 757; double-effect, pain relief hastening death, 739–40; involuntary, 389; “letting nature take its course,” 773; passive, 767, 773; voluntary/active, 707; see also Artificial life support

Expense of care. See Financial issues

Fadiman, A., 453

Faith, 426; see also Spirituality and religion

Faith healers, curanderos (case example), 439, 453–54, 458–59

Families: discussions and interventions for pain management, 397, 398, 399; in early stage of mourning, 576–77; facing catastrophic illness, 51; facing medical bankruptcy, 582; openness to help in bereavement, 573; patients’ difficulties speaking with loved ones about their condition, 510; as potential area for research, 806; roles of, in cases of transplantation, 683–86; social workers’ role in caring for, 548, 565–69; support groups as substitute/extensional holding environment, 511; underdeveloped research areas, 822–3; visits to prisoners, 623–14, 621–22; see also Caregivers; Children

Family assessment: conducting, 548–50; conflicts and communication problems (case example), 551; coping history, strengths, and emotional responses, 558–60; counseling and therapy, 561–62; cultural values and beliefs, 554–56; developmental stage of client and family, 553–54; discharge planning, care transitions, and referrals (with case example), 560, 564–65; factors in, xxiii; family acceptance of advance directive (case example), 552–53; family conferences (with case example), 562–65; mental health risk in end-of-life care, 363–65; nursing home placement, guilt of spouse for (case example), 556–57; past and current medical situation, 550–51; preparing caregivers for end-of-life care responsibilities, 565–66; previous experiences with illness, disability, or death, 557–58; socioeconomic factors and resources, 560–61; spirituality and religion, 556–57; structure, roles, and relationships (with case example), 551–53

Downloaded from cupola.columbia.edu
Family Unity (retreat program): benefits, 657–58; building sense of community, 650–53, 658, 665; “burden bag,” 652, 655; description and case example, 642–43; enhancing family functioning, 649–50; evolution of, 648–49; experiential interventions, 650–53; “family boats” and boat ceremony, 652, 655; Family Unity box, 653, 656; legacy building, 650; moving from fear to mastery (with case example), 651–53, 658; reflection service, 655–56; resiliency and empowerment, 658; rituals, 653–57; see also HIV-affected patients and families

Farber, A., 102–25
Farber, S., 102–25
Farley, W., 32

Fatigue, 553

Fear, 122, 282, 298, 340

Feifel, H., 138
Felton, S., 166–67
Ferris, F., 411, 412

Fetuses, protection of (state interest), 736

“FICA: A Spiritual Assessment,” 194

“Fight or flight” response, 64, 66, 74, 400

Figley, C., 852

Financial issues: ability to obtain necessary medications, 394; aging of baby-boomer generation, xix, 409, 838–39; Americans’ concern about expense of dying, fear of medical bankruptcy, 410, 520; bereavement support, 822; burden on family resources, xxiii, 553; for cancer patients, 704; cost of hospice care, 415, 488; cost of inmate medical care, 611, 618; disparities in access to care for poor and uninsured, 816; early hospice care reimbursed, 817; hospice care, 818–19; innovations in care, 822–23; need for knowledge of, xxi; palliative care, trend toward, 820–21; policy and payment changes, 826–27; poverty as barrier to optimal health care, 468; reimbursement issues for noncurative hospice care or palliative care, 7, 516, 817, 821; of serious, disabling illness for people of working age, 278–79; social work action plan, 845; socioeconomic factors and resources, 560–61; suggested questions to explore patient/caregivers perspectives, 124; transformation of patient needs, 815–16, 823; unreimbursed costs to caregivers, 820; see also Medicare
Fineberg, I. C., 675–92
Folkman, J., 64–65
Folkman, S., 575–76
Forbes, S., 631
Foster, Z., 825–36
Foucault, M., 162
Foundations. See Professional organizations and foundations
Frank, A. W., 51, 120
Frank, B., 634
Frank, S. H., 473
Fraser, V., 634
Freeman, H. P., 444
Friend, R. A., 485
Fulton, R., 838, 898, 899, 865
Funeral Consumers Alliance, 633

Funeral directors, funeral homes, 572, 578, 633
Funerals, 576, 577

Garrett, A., 198

Gender issues: clinical practice implications, 219–21; coping strategies, 216; culturally as well as biologically constructed phenomenon, 209; daughters with power of attorney for healthcare for parents, 217–18; death anxiety, 213; educational implications, 223; intersection with cultural expectations, 208; intervention efforts, 219; male-female differences in bereavement help sought, 573; middle-aged children experiencing loss of parent, 206; occupational role relationships on interdisciplinary teams, 165; policy implications, 220–21;
as potential area for research, 99, 805; relational theory, 213–15; research findings on bereavement, 201–13; social stratification of gender and death, 210–11; support groups, gender-specific, 517–18; theory and research, 207–19; trauma, death, and bereavement in workplaces, 215–16, 218–19; for twenty-first century, 215–19; visitors to male versus female inmates, 614; women as caregivers and hospice volunteers, 210; women as long-term caregivers, 629; women’s movement, 146, 865; women vulnerable to undertreatment for pain, 383, 384, 476, 718

Generalized anxiety disorder, 377

Genocide, 32–33

George, J. K., 781, 801

Gerbino, S., 593–607, 835

Gershwin, I., 243–44

Gessert, C., 631

Ghosts and spirits, 258

Gillham, J., 588

Glajchen, M., 835

Glaser, B., 138

God representation, 195–96

“Good death” compared to respectful death, 102–3, 817

Gorer, G., 133, 138

Gramsci, A., 354

Graves, gravemarkers, tombstones, 131, 132, 140, 206–7, 210, 259

Grief. See Bereavement/grief/mourning

Grief, disenfranchised. See Disenfranchised grief

Griffith, J. L., 104–92

Griffith, M. E., 191–92

Grinnell, R. M., 797

Groopman, J., 58, 66, 68

Groups, clinical practice with: advantages of, 270; attendance policies, 521; benefits of, 508, 510–13, 545; composition of various group membership types, 515–19; dealing with death of a member, 527–29, 559–40; dropouts, 525; for dying children, 335; formation considerations, 513–12; group dynamics, 509–10; member selection, 516–21; rules, 521–22; setting, considerations for patients, bereaved, and institutions, 513–15; social work history in, 508; stage one, orientation/together as individuals, 522–23; stage two, formation/conflict, 524–25; stage three, consolidation/resolution, 525–26; stage four, winding down and termination, 526–27; structure and duration, 519; see also Support groups

Groups, online: benefits, 529, 530–41, 542, 545; clinical issues, 543; concerns for facilitators, 541; format and guidelines, 541, 542; group management issues, 543–44; increasing use of, 529–30, 534–35; licensing, 544; practical matters, 541–42; recruitment, screening, and assessment, 540–41; reimbursement, liability, and state regulations, 544; research, need for, 535; research suggestions for, 545

Groups, telephone: benefits, 529–30, 538–39, 540–41; 542, 545; clinical issues, 543; concerns for facilitators, 541; format and guidelines, 541, 542; group management issues, 543–44; increasing use of, 529–30, 534–35; licensing, 544; practical matters, 541–42; recruitment, screening, and assessment, 540–41; reimbursement, liability, and state regulations, 544; research, need for, 535; research suggestions for, 545

Handicapped individuals. See Disabilities, persons with

Handprints, 326

Harper, B. C., 835

Harris, A., 406

Headstones. See Graves, gravemarkers, tombstones

Healing, 35, 456–57

Healthcare proxies, 597, 598, 625, 688–89, 733–34, 764; see also Advance directives

Health care system: administration, social work action plan for, 545; discrimination inherent in misallocation of resources, 751–52, 753, 840–41; discrimination, social worker’s duty to challenge, 443–48; disparities in care for poor and uninsured, 816; disparities in care for rural versus urban Americans, 841; emergency rooms, 816; evolving social work roles, 826–27; homophobia in, 485; ill suited to end-of-life care, 137; need for leadership and patient-centered change, 816; origins of social work, 825–26; as potential area of research, 812; unprepared for aging of U.S. population, 819; see also Assessment, of larger contexts and institutions; Medical culture

Health Insurance Portability and Accountability Act (HIPAA), 799

Help, as first request by sick and dying patients, 69

“Helping him cry” story, 69

Helplessness, 558, 559, 664

Hematopoietic cell transplantation. See Transplantation

Henderson, S., 593–607

Hendrix, L., 443

Herman-Bertsch, J., 104

Herman, J., 844, 555, 857

Hinduism: belief in transmigration of souls, 258; master’s parable of salt, 39–40

HIPAA (Health Insurance Portability and Accountability Act), 799

Downloaded from cupola.columbia.edu
HIV-affected patients and families: burden of caretaking, anger, resentment, grief, 646–47; case example of “Adam,” 199–202; Double H Ranch Hole in the Woods Camp, 648; expanded literature on, 482; facing isolation, shame, and stigma, 645–46; feeling guilt and anticipatory loss, 645; grief and trauma manifested, 644–45; inadequate research on difficulties, 645; International Conference on AIDS, 643; as people of color facing poverty and crime, 645; projections of number of orphans, 644; psychological resilience on part of gay men, 485–86; separation of orphaned siblings, 647; support systems existing, 644; women, not gay men, as more numerous victims, 207; see also Family Unity (retreat program)

Hockley, R., 848

Hoffman, R., 57–71

“Holding environment,” 39, 30–32, 51

Hole in the Woods Camp (Double H Ranch), 618

Holocaust, 32–33

Homelessness, 468

Homophobia, 482–83, 485

Hope: before bilateral mastectomy (case example), 283; exceeding realistic expectations, 324; in face of uncertainty, 65; feeding denial and resistance, 304; as gain out of loss, 13–14; pursuing every avenue of cure, 68; role in dying process, 304–7; role in interdisciplinary teams, 307–9; sustaining, with continuing loss, 55

Hospice Benefit (Medicare), 8–9, 152, 305, 415

Hospice care: attitudes of nursing home staff toward, 636–37; barriers to, 819; beginnings in England, establishment in U.S., 135, 137–38, 587–88; bereavement programs, 579–80; care in first hospices unreimbursed, 817; as community-based interdisciplinary teams, 133–34; conforming with most Americans’ wishes for end-of-life care, 157; cost issues with technologically intensive care, 415; coverage by insurance plans and Medicaid, 818; for disabled persons, 306; discrimination against home health aide, 458; as expression of bereavement/mourning, 258; expressions of bereavement/mourning in families, 153–54; conforming with most Americans’ wishes for end-of-life care, 157; cost issues with technologically intensive care, 415; coverage by insurance plans and Medicaid, 818; for disabled persons, 306; discrimination against home health aide, 458; as expression of bereavement/mourning, 258; expressions of bereavement/mourning in families, 153–54; ongoing measurement of, 156; underserved populations, 158, 159, 477–81; 445; underutilization of, 456–66; viewed by families as “giving up,” 436–47; viewed by physicians as “failure,” 100, 102, 113, 152, 416; see also Nursing homes; Palliative care

“Hospital psychosis,” 285

Hospital settings: emergency rooms, 816; need for humanization, 726; need for palliative care programs in, 444; percent of all deaths occur-
Index

Interdisciplinary teams (Cont.)

social workers, need for active engagement in, 835; social workers' struggle for recognition on, 829–30; social workers' unique and vital roles, 793; success, respect, and shared decision making, 169; see also Hospital settings

International Conference on AIDS, 643

Internet: bulletin board groups, 542; chat groups, 542; email groups, 542; evaluating information on websites, 543–44; online telehealth consultation, 535; Listserv network, 834; mutual aid groups and websites, 582; resources for end-of-life care, 546–47; see also Websites


Interviewing: assessment and engagement with spirituality and religion, 194–95; caution on mere data collection, 121; for ecological assessment, xxii; focus on illness in context of client's lives, 121; questions for a religious history, 196–98; as small qualitative research project, 99; suggested questions to explore patient/caregivers perspectives, 123–25; see also Respectful death care model

Involuntary euthanasia, 389

Isolation, psychological and emotional: for cancer patients, 696; with geographic dislocation for transplantation patients and families, 886–87; of HIV-affected patients and families, 645–46; of the ill and their families, 50; of inmates of prisons, 624–25; mediating with sense of community, 581; of nursing home residents, 625–39; of patient and families by medical culture, 57; reduction through sense of trust and safety, 657; reduction with participation in support groups, 508, 511, 512, 522; for transplantation patients, 680; witnessing as relief to fears of abandonment, 122

Itin, C., 642–59

Jackson, D. A., 139

Jacobs, C., 588

Jennings, B., 172

Johnson, Robert Wood Foundation, 137, 159, 609–10, 828, 838

Joint Commission on Accreditation of Healthcare Organizations (JCAHO), 381, 842–43

Jones, R., 748

Jordan, A. R., 548–69

Journals and diaries, 326, 403

Judaism: concern about pain interventions, 395; Elijah the prophet ("wounded healer" story), 34–35; Mi Sheberach prayer, 68; mourning for week of Shiva, 258–59, 372; perspective on suffering, 25

Justice, 388, 594, 599–601

Kaiser Permanente, 818, 822–23

Kamisar, Y., 743, 752

Kardiner, A., 855

Karger, W., 273–96

Kark, P., 786

Karl, J., 196–98

Kastenbaum, R., 213

Kearney, M., 859–60

Kevekarian, J., 768

Kirk, G., 448

Klass, D., 144

Klein, M., 248–50

Kleinman, A., 23, 26, 29, 33

Kleinman, J., 23, 26, 33

Kochanowski, J., 139

Koenig, B., 605–6

Kramer, B. J., 792–812

Kreier, R., 451

Kühl-Marxsen, E., 133, 134, 211, 817, 861, 864

Kuhl, D., 851

Kushner, H., 69

Laird, J., 29

Lambek, M., 815

Langer, A., 32–33, 45


Last Acts Coalition, 547, 638, 838, 842

Latinos. See Hispanics/Latinos

Leadership in social work: advancing, 830–31; assertion and solidification of roles and contributions, 825; Brunley's innovative palliative care program at Kaiser Permanente, 822–23; building competency for end-of-life care, 842–43; call to action, 847–49; Chackins's example, 831–32; change in attitudes and values, 825; changes in policy and practice, 8, 9, 15; examples of, 830–31, 834–35; exerting as matter of self-care, 863; expertise advancing practice, 832–33; Foster's example, 827–29; Internet Listserv network, 834; NYU Medical Center programs, 831, 833–34; organizations providing, 842–43; pain and symptom management, 397; palliative care, 420; palliative care evaluation, 421; policy change in end-of-life care, 9; proactive community outreach, 833–34; role models, 835; Smith College School for Social Work course in, 820; Soros Foundation Open Society Institute's Project on Death in America, 137–38, 421, 547, 610, 834; support groups and facilitators, 509, 522, 523, 526, 527, 528–29, 570–71; unified agenda, 840; visibility and recognition, 830; see also Social work, future of

Lee, J. A., 485, 780

Legal issues: Compassion in Dying v. Washington, 745; Cruzan v. Harmon and Cruzan v. Director, Missouri

Downloaded from cupola.columbia.edu
Index 885

Life expectancy: aging baby-boomer generation, xix, 409; 838–39; extension of, 133; formerly fatal illnesses now chronic, 8, 171, 286, 410, 773; 818, 839

Life reviews, 193, 333–34, 361, 593–94, 613

Life support. See Artificial life support

Lifton, R. J., 145

Lindbergh, A.M., 260

Lindemann, E., 141, 254

Linder, J., 696–721

Linking objects, mementos of deceased, 251–52

Listserv groups, 542; see also Groups, online

Living wills, 176, 735, 733–34, 763–64; see also Advance directives

Llewellyn, N., 132

Lo, B., 597

Loewald, H., 247

Loftland, L., 134

Long-term care, 629, 632

Long-term care insurance, 820

Loscalzo, M., 401

Lou Gehrig’s disease, 43–54

Lynn, J., 795

McCrary, S. V., 181

McGoldrick, M., 365

Mahler, M., 251

Managed care: challenges to end-of-life care, 840; controversy and mistrust of, 818; demand for cost-effective practice, 829; impact on U.S. health care system, 839–40; possible advantage, 133; nationalization, 463; stigmatization, 476–77; research considerations, 842; as stigmatization, decrease, with participation in support groups, 508, 511; victims of, as traditional focus of social work professionals, 463; see also Gays and lesbians; Minorities; Older people; Prisons, end-of-life care in

Marshall, C., 801

Martin, T. L., 211

Maslach, C., 850

Maturana, H. R., 162

Mauder, F. W., 623

Mazurh, T., 165

MDS (Minimum Data Set), 634

Meaning making: bereavement and spirituality, 142, 295, 371; diversity of practices, 27; explanatory styles affecting behavior, 588; suffering and, 29–34; through beliefs and rituals surrounding death, 130–33; through “stories,” 120–21; as understanding of illness and challenges, 556; as universal healing need, 428; values and attitudes influencing, 98; see also Spirituality and religion

Means to a Better End: A Report on Dying in America Today, 838

Medicaid, 676, 816, 817, 819–20

Medical culture: death as enemy, dying as “failure of medicine,” 100, 102, 133, 152, 477; difficulty of coping with dying patients, 710;
Monroe, B., xx, xxi, xxv
Mood disturbance, 367–72
Moon, M., 815
Morgan, J., 425
Morrow-Howell, N., 800
Mortality. See Dying and death;
Social workers, facing own mortality
Mor, V., 677
Moss, M. S., 206, 348
Moss, S. Z., 206, 348
Mount, B., 859
Mourning. See Bereavement/
grief/mourning
Moyers, B., 137, 547
Mtezuka, M., 349
Muller, W., 716
Multi-axial Assessment (DSM-
IV), 362
Multicultural issues: advance
directives, lower prevalence of,
774; applying cultural framework to end-of-life sit-
uation, 448–50; assessment by social worker, xxiii, 269,
450–52; authority figures, deference to and reluctance
to question, 455–56; autonomy and truth telling about
terminal diagnosis, 603, 773–74; conceptual framework, developing for
end-of-life care, 443; connections with deceased, 237;
coping styles, 613; cross-cultural communication,
454–56; cultural competence as key for social workers,
841–42; culturally sensitive models of care, need for, xxi,
410, 440–42, 450–58; culture, definition of, 442–43, 446;
discussions and design of respectful end-of-life care, 8,
108–9, 110–11; dying and bereavement, 128–29; end-of-
life tasks, 709; explanatory models of illness, 452–54;
faith healers, curanderos (case example), 439, 453–54,
458–59; foreign language versions of educational
materials, 476; grief, variations in rituals and expres-
sions of, 208, 257–59, 372–73; language barriers, inter-
preters, and translators, 396, 440, 452, 456–58, 465–66,
475, 476, 686; from melting pot to cultural mosaic, 444;
mental health risk in end-of-
life care, 356; minorities unassimilated or unidentified
with majority culture, 462–63; mourning behaviors,
577; pain management assessment, 392–93; pain relief versus clarity of mind
at end of life, 709; pain, reluctance to admit to
suffering from, 567; patient's view of reality taking prece-
dence, 441; as potential area for research, 805; in prisons,
612–13; requiring transformation of institutional systems,
447–48; rituals surrounding death, 192, 424; serious
illness, implications of, 279; social, economic, language
barriers, 440, 465–66, 475; social worker's self-
evaluation, 442; support groups for, 517; transformative questions for social
workers, 446–47; transplantation and end of life, 689;
traumatized children, 671–73; underserved populations
for hospice care, 158, 159, 417–18
Multidisciplinary teams,
167–68; see also Interdisci-
plinary teams
Music, 398, 399, 400, 500
Myss, C., 436
National Association of Social
Workers (NASW): Client
Self-Determination in End-
of-Life Decisions policy
statement, xix–xx, 175–79,
179, Code of Ethics, 172–73,
179, 184, 544, 547, 607,
841–42
National Cancer Institute “Fact
Sheet on Depression and Cancer,” 369
National Center for Grieving
Children and Families,
586
National Hospice and Palliative
Care Organization (NHPCO), 154, 155, 834
National Hospice Social Work
Survey, 155, 156
Native Americans. See American
Indians
Neimeyer, R. A., 30, 143
Newman, J. S., 428
NHPCO (National Hospice
and Palliative Care Organiza-
tion), 154, 155, 834
Nicholas, P. K., 161–69
Nickman, S. L., 214
911, calls to emergency response
teams, 591, calls to emergency response
teams, 598
Nonmaleficence as bioethical
principle, 174, 182, 388, 594
Noppe, I., 260–261
Nouwen, H., 34–35, 859, 860
Nuland, S., 117
Nurses: approaches on interdis-
ciplinary teams, 163–66;
mostly female, 210–11; occupa-
tional role relationships on interdisciplinary teams, 165, 166
Nursing homes: challenges of
managing for quality care,
638–40, 849; demographics of patients in, 628–29; disen-
franchised grief of staff
nurses, 858; “Do Not Hospi-
talize” orders, 655; grief after
death of resident, 357, 637–38; as “heaven’s waiting
room,” 640; hospice care, residents not receiving, 849; hospice care, staff attitudes
toward, 636–37; negative comments about terminal
care, 640; neglected populations in, 271; percent of
deaths in, 411, 628, 640; physical and/or cognitive
decline, 629, 640; placement of loved one as wrenching
decision, 631; systematic undertreatment for pain, 7,
383, 384, 444; trend toward institutionalizing persons
close to death, 640
Nursing homes, social work
interventions in: assessment
and care plan meetings,
633–35; benefits of, 639–40;
bereavement care, 637–38;
Nursing homes, social work interventions in (Cont.) challenges to, 639; hospice enrollment, 653–57; hospital transfers, 653; lack of hospice care in, 819; upon admission, for patients and families, 650–53
Nursing Leadership Consortium on End-of-Life Care, 843
Nutritional guidance, failure to provide, 60
NYU Medical Center: Doula to Accompany and Comfort program, 833–34; Palliative Care Consultation Team, 835
Obituaries, 210
Object relations in bereavement, 248–54
O’Connor, S. D., 738, 739
O’Donnell, P., 171–84
O’Donohue, J., 860–61
O’Donnell, P., 171–84
Older people: bureaucratic projection of fears onto, 357;
as stigmatized and isolated group, 268; victims of ageism, 348–59; vulnerability to undertreatment for pain, 383, 384, 718; welfarization of, 350
Oman, D., 426
Oncology. See Cancer
Open Society Institute.
Oregon: assisted-suicide law (Death with Dignity Act), 218, 389, 747, 748, 761, 768, 769–70; Dougy Center for grieving children, 385–86
Orentlicher, D., 751
Organ donor programs, 633
Orientals. See Asians
Osteosarcoma, 57–71
Otis-Green, S., 462–78
Pain and symptom management: acceptance of patient’s report of, 382, 391, 394–97; addiction, concern for, 409–73; 567, 718; affective components of pain experience, 394; assessment, 125, 268, 314–15, 391–97; 566–67; behavioral aspects of pain experience, 394–95; as best of clinical social work practice, 380, 397; caregiver’s nonadherence to plan of care, 717–19; cognitive dimension of pain, 387f; 394; cognitive impairment or loss of verbal ability, complications of, 395–96; cognitive restructuring/reframing, 399–400; 567–68; complications with substance-use disorder, 472–73; constitutional issue and chilling effect of Oregon v. Ashcroft, 749; coping statements, 400, 568; distraction, 400; double effect, principle of, 388–89, 739; environmental aspects, 395; ethical issues, 387–91; as ethical mandate, 381; family decision making for, 390–91; hypnosis, 402, 568; imagery and visualization, 402–3, 568; interventions, clinical, 397–99; interventions, medical/pharmacologic, 397; involuntary euthanasia, 386; legal issues in Bergman v. Eden Medical Center, 740; legal protection for doctors for double-effect euthanasia (pain relief hastening death), 739–42; minimization or magnification through filter of family or caregivers, 386–87; as model for integration of principles, 381; operational definitions, 386–87; opioid analgesics, some pharmacies’ reluctance to stock, 394, 444, 469; palliative sedation in the immediately dying, 389; patient/family/caregiver barriers, 383–86; patient’s hiding or “toughing it out,” detecting, 296; pediatric, 322, 383; as potential area of research, 808–9; “redemptive” pain, 383–84; relaxation techniques, 400–401; self-monitoring with diaries and journals, 403–5; social/economic variables, 394; spiritual/existential/religious dimensions, 395; suffering and, 387; symptom relevance, 381–82; system/practitioner barriers, 382–83; terminal cancer patients, 709; transplant patients, 687–88; undertreatment, groups vulnerable to, 7, 383, 384, 444, 718; see also Palliative care
Palliative care: in acute-care setting, withdrawal of treatment, 177; barriers to, 821; benefits to health care system, 422–23; disabilities, persons with, access to care, 503–7; in face of rejection and hostile challenge, 69–70; failures of oncological professionals, 67, 68–69; few physicians certified in, 8; goals and ideals, 9, 71, 150, 409, 411; hospice care, comparison to, 413; hospice settings, barriers to care, 413,
Index 889

415; innovative program of Kaiser Permanente, 522–23; Last Acts Coalition concept and precepts of, 524; medical education only beginning to address, 816; need for, 411, 414, 415, 418–19; origin of term, 412; physicians melding with families’ strength, 58; in prisons, through interdisciplinary teams, 620–21; problems with interdisciplinary teams, 168; providing empathy, compassion, sharing of suffering, xx–xxi, 54–57; providing “holding environment,” 39; providing personal connection, xx; question of legal right to, 749–50; question of terminal sedation and physician-assisted suicide, 750, 753; reports on, 413; similarities to prison work, 780–82; social workers’ inadequate preparation for, xix–xx; social workers’ role in, 268, 409, 410–21, 422; team specialization, 412; trend toward, 820–21; typical programs and comprehensive model, 442; see also Hospice care; Pain and symptom management

Panic attacks, air hunger, 703

Papadatou, D., 857–58

Parker, C. M., 143, 255, 580

Parkinson, F., 855

Partners in Care Foundation, 822–23

Passive euthanasia, 767, 773

Pathfinders self-care program, 585

Patient’s Bill of Rights (American Hospital Association), 152

Patient Self-Determination Act (PSDA), 467, 476, 603–06, 612, 613, 733–34, 761, 762

Pattison, E. M., 483

Payne, R., 444

Pellegrino, E., 163

Peripheral stem cell transplantation. See Transplantation

Personal experience, suggested questions to explore patient/caregivers perspectives, 125

Physician-assisted suicide: as adjunct to adequate pain management at end of life, 748; arguments against, 178, 768; arguments for, 768–69; autonomy, self-determination, and rational control of dying, 752–53; comparison to euthanasia, 177, 767; Compassion in Dying v. Washington, 745; concern over depression and relationship to suicide, 737; constitutional background, 744–47; description of, 389; as discriminatory and legally unacceptable, 736; double-effect pain medication and potential criminal liability, 750; due process protections, 748; ethical issues, 177–79; gender issues in decision making, 218; Kevorkian, J., 768; leading to legislation, 137; legal issues confusing, 742–44; mistrust of clinicians by minorities, 384; as option in palliative care, 750; Oregon’s Death with Dignity Act, 218, 389, 747, 748, 761, 768, 769–70; Oregon v. Ashcroft, state versus federal authority, 748–49; polls indicating public favor, 768; professional support and reports of patient requests for, 769; Quill v. Vacco, 746–47; role of medical profession, 751–52; as “slippery slope,” 751, 756; U.S. Supreme Court ruling on criminalization, 743; Washington v. Glucksberg, 746, 748, 751–52; see also Suicide

Physicians: approaches on interdisciplinary teams, 165–66; few certified in palliative care, 8, 158; help for bereaved, 579; medical profession’s ethical integrity (state interest), 736; protecting patients from truth of diagnosis, 704; reluctance to “abandon” patients to hospice care team, 819, 821; sharing of responsibility by, 165; use of term “discipline,” 162–63; see also Medical culture

Piaget, J., 234

Pieta of Michelangelo, 139

Planned Parenthood v. Casey, 745

Play with ill children, 332–33

Poetry: as communication with lost loved ones, 21–22, 40–41; as request to be remembered, 242; as spiritual expression, 188–89; usefulness of, 73

Popkin, M. K., 368, 399

Postadults, 349

Post-traumatic stress disorder (PTSD), 81, 376–77, 665–66

Potash, J., 786

Power issues: on interdisciplinary teams, 165; for professional organizations, 162

Power of attorney for healthcare, 176, 217–18, 655, 733; see also Advance directives

Prayer, 196, 259, 399, 430–31

Prayer, 196, 259, 399, 430–31

Pregnancy loss, association with PTSD, 85, 376–77.

Piaget, J., 234

Pieta of Michelangelo, 139

Planned Parenthood v. Casey, 745

Play with ill children, 332–33

Poetry: as communication with lost loved ones, 21–22, 40–41; as request to be remembered, 242; as spiritual expression, 188–89; usefulness of, 73

Popkin, M. K., 368, 399

Postadults, 349

Post-traumatic stress disorder (PTSD), 81, 376–77, 665–66

Potash, J., 786

Power issues: on interdisciplinary teams, 165; for professional organizations, 162

Power of attorney for healthcare, 176, 217–18, 655, 733; see also Advance directives

Prayer, 196, 259, 399, 430–31

Pregnancy loss, association with isolated grief, 494

Preparatory play with ill children, 332–33

The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical Research, 177, 180

Prisons, end-of-life care in: advance directives, 784; advantages of social workers in cell blocks, 779–80; advocacy of amelioration of prison and sentencing systems, 69–20; aging and ill falling victim to intimidation or violence, 645; aging prisoner population serving longer sentences, 60–12, 788;
Index

890 Prisons, end-of-life care in (Cont.) community and family, sense of, 785, 786, 788–89; death as normal process, 785; dehumanizing settings, 271; discharge planning, 623; disenfranchised grief in, 787; DNR orders as approval of lesser standard of care, 784; duty of care, positive and negative effects, 784–85; dying alone as antithesis of good care, 782–83; family visits, 613–14; feelings of isolation, 624–25; framing work of care, 785–89; hospice and palliative care (with case example), 616–17; hospice care for terminally ill prisoners, 783; inmates among most vulnerable populations, 625; inmates as causes of own distress, 779; lack of understanding of meaning of advance directives, 610; life reviews, 613; loneliness and finality of death, 782; loss as familiar and ubiquitous, 618; magnification of impact of debilitating illnesses, 612; medical parole or family visits for terminally ill, 621–22; multicultural issues, 612–13; need for research, 624; need to restructure prison health care system, 611–12; obstacles to social work or ecological perspective, 779; palliative care, similarities to prison work, 780–82; palliative care through interdisciplinary teams, 620–21; prisoners’ view of death in prison, 614–15, 626; respect for individuals, 786–87; rights of prisoners, 662–63; social workers as facilitators, 615–16; social workers’ role for terminally ill inmates (with case example), 623–24, 625; social work, key areas for contribution, 781–82; social work’s unique role, 778–80, 789; structure and organization, 785; sudden death in, 789; support groups for, 517; suspicion of system, 609; trained inmates helping with care, 412, 616–17; women, 614 Privacy and confidentiality issues, xxiv, 61, 521 Professional organizations and foundations: action plan, 845; AOSW (Association of Oncology Social Work), 179, 835; Association of Oncology Social Work (AOSW), 179, 835; Canadian Hospice Palliative Care Association (CHPCA), 411, 412; Cancer Care (social work agency), 834, 835; Compassionate Friends (support groups), 145, 582; Compassion in Dying organization, 745, 768; Council on Ethical and Judicial Affairs, 82, 764; Double H Ranch Hole in the Woods Camp, 648; Dougy Center, Oregon, 586; Education for Physicians in End of Life Care (EPEC), 172, 477, 547, 767; End-of-Life Demonstration Project, 137; End of Life Nursing Education Consortium (ELNEC), 477; Funeral Consumers Alliance, 63; Human Rights Coalition, 493; Institute of Medicine, 477, 836; Joint Commission on Accreditation of Healthcare Organizations (JCAHO), 381, 842–43; Michigan Partnership for the Advancement of End-of-Life Care, 159; Missoula End-of-Life Demonstration Project, 137; National Association of Social Workers (NASW), 544, 547, 607, 770, 840–42; National Center for Grieving Children and Families, 586; National Hospice and Palliative Care Organization (NHPCO), 134, 155, 834; Pathfinders self-care program, 585; Project on Death in America, 137–38, 421, 547, 610, 834, 843; Robert Wood Johnson Foundation, 137, 159, 609–10, 828, 838; Social Work Leadership Awards, 843; Social Work Leadership Summit on End-of-Life and Palliative Care, 421, 843; Social Work Summit on End of Life and Palliative Care, 843; Society for Social Work Leadership in Health Care, 843; Soros Foundation, 137–38, 421, 547, 610, 834; TEAM (Together Everyone Achieves More) services, 642; United Hospital Fund, 828; Victoria Hospice Society (British Columbia), 862; West Coast Center for Palliative Care and Research, UC Davis, 622; Widowed Persons Service (AARP), 145, 583; see also Family Unity (retreat program) Professionals, description of, 162 Project on Death in America: Social Work Leadership Awards, 843; of Soros Foundation Open Society Institute, 137–38, 421, 547, 610, 834, 843 Proxy directives, 597, 598, 635, 733–34, 764 PSCT (peripheral stem cell transplantation). See Transplantation PSDA (Patient Self-Determination Act), 467, 476, 603–6, 632, 633, 733–34, 761, 762 Psychosocial issues. See Family assessment; Mental health issues Public guardians of disabled persons, 305–6 Puerto Ricans, expressions of bereavement/grief/mourning, 258 Pulchalski, C. M., 194, 556 "Quest stories," 31–32 Quill v. Vacco, 746–47 Quinlan, K. A., 135, 816
Index

Rando, T., 32, 68, 218, 365, 367, 435
Raphael, B., 144, 587, 860
Raymer, M., 150–59
Reconciliation, suggested questions to explore patient/caregivers perspectives, 125
Recreation, 651–52
Reese, D., 150–59
Referrals, 158, 182, 270, 548–49, 560, 564–65
Rehnquist, W. H., 747
Reid, J. D., 485
Reinhart, S., 745
Reivich, K., 588
Relational theory, 220, 227–28
Relationships: authentic, on part of clinician, 265–66; social support as, 575; as spiritual commitment, 102; suggested questions to explore patient/caregivers perspectives, 124–25
Relaxation techniques, 400–401, 500, 702
Relf, M., 580
Religion: Buddhist perspective on suffering, 24; Christian perspective on death and suffering, 24–25, 131–32; compared to spirituality, 191–92, 425–26; role in end-of-life care, xxvi; see also Judaism; Spirituality and religion
Remen, R. N., 67, 68, 69, 858
Renzenbrink, I., 848–66
Resch, N., 206
Research in social work conceptual frameworks: absence as detrimental to professional standing, 793–94; action plan, 844; analytical pitfalls in literature, 208–9; arenas, medical and non-medical, 796; barrier to, 795–99; conceptual and methodological issues, 803–2; findings on bereavement, 211–13; funding, 799; journals in end-of-life care, 797, 804; online and telephone support groups, 535, 545; marginalization of the dying and bereaved, 475–76; need for empirical studies, scientific foundation of practice, 793–94; need for social work view in addition to medical, 792–93; policy analysis and development, 803; potential areas for, 805–12; recommended scope across multiple settings, 795–96; on roles of nursing home social workers, 639; social workers as contributing partners, 797–98; social workers as knowledge creators and disseminators, 798–99, social workers as research consumer, 797; studying established priority areas, 803–4; within correctional setting, 625; see also Assessment, of larger contexts and institutions; Theory, issues of
Resignation, 283
Resilience, 658, 665
Resources: social worker’s knowledge of, xxiii; see also Financial issues
Respectful death: Americans’ preference not to be hooked up to machines, 410; aspects of, 102; care at home, 410; compared to “good death,” 102–3, 817; debates over assisted suicide and technologically prolonged life, 152, 176–77, 217, 302–3; 409, 410, 464, 589, 611, 725; 737, 753, 761, 815–16, 823; description of, 103; implications for social work practice, 114; Joan’s sister Barbara’s failure to receive, 1–5; in multiple contexts, xxvi; sharing of suffering, xxvi; values and attitudes promoting, 98; see also Self-determination
Respectful death care model: bridging cultural gap, 110–11; case studies, 112–13, 115, 116–17, 122; challenging standard professional and personal boundaries, 115; clinician as consultant, collaborator, and guide, 115; difficulties faced by clinicians, 112–13; family caregivers, 109; healthcare team, 110; ill persons, 109; interdisciplinary system of care, 118–19; with patient in center of system, 123; process versus prescription, 103–4; proposed protocol for exploring, 11–12; research-based, 104–7; self-knowledge of one’s own response to loss, 118
Rich, B. A., 741, 765
Rituals of burial, 192; cultural considerations, 576; of ending and termination, 199–202; at Family Unity (retreat program), 653–57; funerals, 576, 577; memorial services, 568; of mourning and healing, 427; therapy as form of, 427; varying across cultures, 424
Rizzuto, A., 105, 484
Robert Wood Johnson Foundation, 137, 159, 609–10, 528, 838; Last Acts Coalition, 547, 638, 538, 542; SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment), 381, 413, 765, 794, 795, 820, 842
Robinson, D., 206–7
Rolland, J. S., 325
Rosenberg, D., 25
Rosenblatt, P., 139
Rosner, F., 786
Rossetti, C., 242
Rossman, G., 801
Royal Commission into Aboriginal Deaths in Custody (RCIADIC), 782
Rubin, S., 143
Runcie, R., 857
Rutland, C. B., 462–78
Ryan, M., 781
Sachs, J., 190
Safety, sense of, 657, 663–65, 666–68
St. Christopher’s Hospice, London, 786

Downloaded from cupola.columbia.edu
Salt, Hindu master’s parable of, 39–40
Sanctity of life (state interest), 736
Saunders, Dame Cicely, xxvi, 135, 151, 786, 817, 828
Scanlon, J. M., 436
Scapegoating in support groups, 524–25
Schechter, N. L., 380
Schuman, W. H., 477
Schut, W., 262, 352, 591
Schwarz, V., 30
Secondary trauma, hospital workers experiencing, 85–88, 90
Self-care: anam cara (soul friend), 860–61; balance between home and work, 862; burnout, xxvi, 83; caregiver grief and stress, 848–49, 857–58; compassion fatigue, 477, 852–53; education, 862; grief and mourning, 862; grieving over death of patients, 317; inner bereaved child, 860; making a difference from personal to political, 862–63; minding oneself, 861–63, 869; psychological trauma and healing, 854–57; renewal of hope and purpose, 870; Renzenbrink’s personal and professional reflection, 863–66; sharing personal reactions for mutual support, 858; social workers as intimate strangers yet surrogate relatives of dying or deceased, 859; soul pain, 860; stress management, 862; supervision, 861; support programs, 50–62; teamwork and “cappuccino therapy,” 862; therapy, 861; values, 861; vicarious traumatization, 853–54; wounded healers, 859–60, 864–65; see also Vulnerability of social workers
Self-determination: balanced with family common good, xxi; as core value of hospice care and social work, 150, 155; debate over physician-assisted suicide, 752–53; derived from principle of autonomy, 594; patient autonomy versus physician’s paternalism, 171; Patient Self-Determination Act, 467, 476, 603–6, 612, 633, 733–34, 761, 762; potential conflict in respectful death care model, 116–17; social workers’ allegiance to autonomy, 864; support for values and desires, xxi, xxvi; see also Advance directives; Autonomy
Seligman, M., 588
Senior citizens. See Older people
September 11, 2001: deaths, witnesses, and PTSD, 663; gender considerations for trauma and death in workplaces, 215–16; gender issues in, 218; highlighting need to understand mourning process, 233; reflections on living with dying, 72–91; see also Disasters and sudden traumas
Settings: awareness of influences of, 272; as contexts with values, attitudes, beliefs, and traditions, 97–98; of deaths, percent in hospitals, nursing homes, etc., 411; of support groups, considerations for patients, bereaved, and institutions, 513–15; underdeveloped research areas, 802–3; see also Hospice care; Hospital settings; Nursing homes; Prisons
Sexuality, 303
Shannon, S., 163
Sheldon, F., 781
Silver, L., 72–91
Simmons, J., 815–23
Skills of social workers: caring, 164; compassion, 54–56; diversity of, 14–16; empathy, 164; ethical issues, 193; overview, xxi–xxii; see also Assessment; Clinical practice; Social work profession
Smith College School for Social Work, 12–13
Snyder, L., 178
Sobriety (cases of former substance abuse), 470
Social Work Assessment Tool (SWAT), 156
Social workers, facing own mortality: addressing denial, deriving meaning from death, 297; coming to grips with many deaths, 864; distancing from client, 502; knowing oneself, 266; as listening presence, xxv, 3–4, 6, 9, 123; self-knowledge of response to loss, 118; understanding one’s own reasons and motivation, 852; see also Self-care; Vulnerability of social workers
Social work, future of: aging of U.S. population, 838–39; building competency for end-of-life care, 842–43; building multicultural competency, 841–42; challenging discrimination inherent in healthcare system, 751–52, 753, 840–41; impact of managed care, 839–40; more and better education in end-of-life care, 838; see also Leadership in social work
Social work in end-of-life care: at-risk and underserved populations, spokespersons for, 9, 755; attitudes necessary for, xxi–xxii; as “calling,” 172; crisis-oriented nature of, 549; curriculum development, 12–13; cutbacks in staff, 312; disaster relief critical resource, 72; 73; ethical issues, recommendations, 183–84; goals for this book, 6–7; hospice care, 153, 154–55; interdisciplinary teams, approaches, 163–66; legal issues, inev-
Index 893

Social work profession: allegiance to autonomy, 164; caregiving, 754; neutrality and boundaries, xxi, xxv, 79; palliative care role, xxi–xx, 419–21; policy change, new programs, and advocates, need for, 9, 156–57, 725, 754; research, potential areas for, xx, 805; respectful death care model, implications of, 114; role of, xxi–xxi, 114–18, 754, 827, 828–29; service delivery, gaps in, 7–8; serving minority poor populations, 841; shortage of gerontologists, 839; poor populations, 841; shortfalls in, 7–8; serving minority populations, 828–29; service delivery, gaps in, 7–8; serving minority poor populations, 841; shortage of gerontologists, 839; training, deficiencies in, 797; values, 778; witnessing
Social Work Leadership Awards, 843
Social Work Leadership Summit on End-of-Life and Palliative Care, 421, 843
Social work profession: allegiance to autonomy, self-determination, 164; “calling,” 172; as caring, compassionate, and thoughtful, 826; cutbacks in staff, 312, 566; duty to challenge discrimination in health care system, 445–48; erosion of autonomy and influence, 830; evolving roles, 826–27; heavier workloads, lower job satisfaction, 848–49; integrating personal with professional, 805; legitimation and expansion as core profession, 826–29; low status, 826; narrowing of demand, 557; NASW Code of Ethics, 172–73, 179, 184, 544, 547, 607; National Association of Social Workers (NASW), xix–xx, 178–79, 779; origins, 825–26; social worker as anxiety-containment vessel, 282; social worker as conduit, mirror, guide, and ally, 293; social worker as consultant, guide, 16; struggle with self-esteem and identity, 825; suitability for involvement in ethical issues, 172; traditional role in community resources and protective support systems, 827; unfavorable environment in healthcare field, 836; see also Leadership in social work; Research in social work conceptual frameworks; Social work in end-of-life care
Social Work Summit on End of Life and Palliative Care, 843
Society for Social Work Leadership in Health Care, 843
Sons: middle-aged, experiencing loss of parent, 206; serving with power of attorney for healthcare for parents, 217–18; see also Gender issues
Sormanti, M., xix
Soros Foundation: Open Society Institute Project on Death in America, 217–18; work with patient and family, 117; “chaos stories,” 51; creating within patient’s plus families’ values, 104;

Downloaded from cupola.columbia.edu
Stories, as meaning, continuity, sense of identity (Cont.)

defining hopes and dreams for patient’s remaining time, 114; eliciting in discussions with patients and caregivers about end-of-life care, 112; by families in collective life reviews, 56; as form of mourning ritual, 47;

“helping him cry,” 69;

Hindu master’s parable of salt, 39–40; importance in assessment, 120–21; as lenses for understanding views of living and dying, 98; life review and preview with dying children, 333–34;

“making a difference to starfish,” 71; as narrative therapy, 587; need to suspend preconceived notions, 107;

play and “storywriting” with ill children, 33–33; prisoners,” 787; “quest stories,” 51–52; sharing in, as therapeutic for all, 123; of terminally ill children, 345;

“words upon our hearts,” 195; “wounded healer” tale, 34–35; see also Ethnography Strauss, A., 138
Stroebe, W., 147, 262, 352
Stroebe, M., 147, 262, 352

Substance-use disorders, 469–73

“Substituted” judgment, 467, 504, 597, 733, 764

Suffering: caregivers’ encounters with, 34–40; categorization as inauthenticating, 29; ethnography of, 23–27; historical understanding, 35–36; as loss of personhood, 26–27; and meaning making, 29–34; medical perspective on, 26–27; and pain and symptom management, 387; as perception of threat to self, 120; role of witness to, xxv; spiritual and religious views of, 24–25; suggested questions to explore patient/caregivers perspectives, 125; as surrenders to new sense of reality, 27; “tragic vision” of, 32

Suicide: gender-related in bereavement, 212–13; prevention of (state interest), 736–37; risk of, in cancer patients, 704; risk of, in persons with disabilities, 501; by those who survive loved ones, 464; thoughts of, indicating possible depression, 371; see also Physician-assisted suicide
Sulmasy, D. P., 178
Superego in mourning, 247

Supervision, for clinical social workers, 315–17

Support groups: benefits of, 510; bereavement, 580–81; camp programs for terminally ill children, 336, 337; cancer patients, 705; for children facing death of loved one, 516–17, 568; compared to psychotherapy groups, 580–10; Compassionate Friends, 145; development through “Project Liberty” after September 11, 91; growing network of, 145; mutual-aid and self-help programs, 581–83; for social workers, 586–62; Widowed Persons Service (AARP), 145, 583; see also Groups, clinical practice with SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment), 381, 413, 765, 794, 795, 820, 842
Surrasc tie decision makers, 175, 176, 465, 504–5, 532, 563, 733, 740–41, 754
Sutton, A. L., 588–31
Swanson, J. W., 181
SWAT (Social Work Assessment Tool), 136

Talmud, 24–35
Taylor-Brown, S., 549, 559, 561, 566, 642–59
TEAM (Together Everyone Achieves More) services, 642

Telemedicine, 622

Terminal sedation, 750, 751
Terrorism, 32–33

The Hospice Heritage, 835

Theory, issues of: analytical pitfalls in research literature, 208–9; bases, xx; caution on absence of data, 209; at core of social work in end-of-life care, xx–xxi; as critiqued hypothetical explanations, 98–99; as works in progress, 99; see also Assessment, of larger contexts and institutions; Research in social work conceptual frameworks

Therapeutic relationships, 110, 111, 310–11

Therapeutic touch, 398

Third parties, innocent, protection of (state interest), 736
Thompson, B., 482–95
Thompson, N., 438–58
Thompson, S., 348–58
Thoresen, C. E., 467
Thurman, H., 37
Tillman, T., 623

durational, 45

Time, chronological versus durational, 45

Tombstones. See Graves, gravemakers, tombstones

Touch, therapeutic, 398

Training in end-of-life care: curriculum development, 12–13; inadequacy for social workers in hospices, 157–54; inadequacy of, xxi–xxii; for medical professions, 161–62; needed in attitudes and skills in support of respectful death, 114, 123; needed in ethical issues, 184; need for preparatory curricula, 9; need for social worker leadership in improving, 8; of older people, 355–56; optimizing family conferences with interdisciplinary teams, 513

Transference, 84


Transplantation: age limits, 600–601; applications, 677–78; avoidance of discussion of risk of death, 675; caregivers and family, 679;
Index 895

transplantation and end of life: advance directives and healthcare proxies (with case example), 688–89; bereavement of family, 692–94; bereavement of staff members, 694; causes of death, 680; family conferences, 688; geographic dislocation, 680, 687; ICU setting for patients with serious complications, 679; multicultural issues, 689; pain and symptom management, 687–88; patient and family unprepared (with case example), 684–85; role of social workers, 681–92; spirituality and religion (with case example), 688–90; timing in relation to illness (with case examples), 681–83; timing in relation to patients life cycle (with case example), 684–85; timing in relation to transplant trajectory (with case example), 684–85; timing of death, 680, 685–86

trauma. See disasters and sudden traumas

traumatization, vicarious, 583–58

Travis, S. S., 638

treatments: avoiding or delaying, 279–81; for cancer, 699–700, 705–71; in cases of medical futility, prolonging dying process, 179–83, 358–59, 405, 410, 599–601; for depression, worsening symptoms, 467, 501; legal presumption in favor of, 737; medications affecting behavior and cognition, 504; unwanted, early policy effort on stopping, 866–75; weighing against suffering and expense, 866; withholding and withdrawing, 176–77; see also transplantation

tronto, j., 27–28

trust, 657, 665

truth telling: cultural attitudes, 773–74; to dying children, in age-appropriate manner, 332–33; informed consent, 594, 596, 598; physicians' struggle with, near end of life, 596; required for trust in patient-doctor relationship, 666; versus protecting patients from truth of diagnosis, 354, 596, 603, 773–74; see also communication

turkey, earthquake, 662–63

vachon, m., 851–52

values and attitudes: in family assessment, 554–56; influencing meaning making as well as resources, 98; inherent in concept of "good," 103; providing context for prospect of death and bereavement, 128–29; workbook for patients and families reflecting on, 106–7; see also ethical issues; multicultural issues

values history as adjunct to advance directive, 735, 742, 766

van gennep, a., 138

veninga, r., 850

victoria hospice society (british columbia), 862

victoria, queen of great britain and ireland, 132

vis, s. g., 704

visualizations and imagery for pain management, 402–3, 500, 568

voices in mourner's world as metaphor, 227–28

volkan, v., 252–53

vulnerability of social workers: connection with own suffering, xxiii, 6, 29, 40; evoking "fight or flight" response, 64, 66, 74; hospital workers experiencing secondary trauma, 85–88; medical staff's methods of handling, 60, 69; need to process own and others' suffering and grief, 12, 22, 107, 115; surviving and sharing, 44–45; see also self-care; social workers, facing own mortality

walco, g. a., 380

wald, f., 151, 828

warn, k., 360–78, 549, 559, 561, 566

walsh, f., 365

walsh, r. p., 139

walter, t., 130

warrier, s., 442

washington v. glucksberg, 137, 747, 748, 752–62

websites: evaluating information on internet, 543–44; funeral consumers alliance, 653; health insurance portability and accountability act (hippaa), 799; last acts coalition, 547, 638; listserv network, 834; medicare, 636; mutual aid groups, 582; resources for end-of-life care, 546–47; transplantation issues, 695; see also internet

weisman, a., 120, 124

west coast center for palliative care and research (uc davis), 622

widowed persons service (aarp-based support groups), 145, 583

Downloaded from cupola.columbia.edu
Index

Widowhood: bereavement experiences, 212; connecting to deceased, 255; duration of bereavement, 11; as focus of studies of grieving, 209; gender-related implications for practice, 209–21; loss of sense of self, 234–35; maintaining relationship with deceased, 144; relational theory, 213–15

Williams, M., 797

Winnicott, D. W., 195–96, 250

Witnessing, being a listening presence: with accompanying feeling of anxiety and horror, 32; alleviating fears of isolation and abandonment, 212, as aspect of discussions with patients and caregivers about end-of-life care, 212; in face of suffering, 120; facing loss, and being "more present," 14; as honor, xxvi; as humbling and spiritual, 869; as key task, xxiii; pain of "chaos stories," 51; as personally difficult, 851; rather than "fixer," 107; at request by sick and dying patients, 69; requiring attunement to one's own suffering, 9; with terminally ill and families, 716; without expecting change, 53; without rushing to relieve suffering, 212–22

Wolterstorff, N., 31

Women. See Gender issues

Women's movement, 146, 865

Worden, J. W., 143

Workplace, gender issues in, 216


Yalom, I., 298

Zabora, J. R., 550

Zilberfein, F., 297–317