

Index

Adjustment Disorder, 107-110 for families, 96-99 ADLS. See Australian Data Linkage length of illness as factor, 98-99 System for parents, 96-99 adolescents. See also emotional impact family support programmes, 101 Family Resilience Theory, 101 emotional impact on, 9, 19-21 questions for, 25 hospital-based, 101 relationships with professionals, 23 hospital visits and, 98 engagement strategies for, 60-61 long-term impact of, psychological age-appropriate, 65, 70-71 effects, 103-104 card activity for, 74 perceptions of, 93-96 preparations for, for children and health care professionals' roles in, adolescents, 93-96 60 - 61preparation for parents, 67 coping skills in, 95 recommendations and guidelines during palliative care, 94-95 special needs for, 107-110 evidence-based interventions for, support strategies for, 104-107 78 - 82treasure box intervention, 110 components of, 78-79 Birth Registrations, 49 information sources for, 62-65 buddy system approach, to self-care, 120 child-friendly bibliography, 69, 72-74 burnout, 116-117 parents as, 62-65 symptoms of, 117 recommendations of, 66 international contexts for, policy Can Teen Australia, 105-107 guidelines for, 54-55 cancer, as chronic illness, 2-3, 29 impact of cancer on, 55-57 card activity, 74 peer support for, 65 child-oriented social supports, 61 preparations for hospital visits, 68-69 children. See also emotional impact psychological adjustments to cancer, 3 age-appropriate cancer terms for, 68 Africa, policy guidelines for cancer in, 57 emotional impact on African Americans, cultural contexts for, questions for, 25 53-54 school-age children (9-11 years), age-appropriate cancer terms, for 18 - 19children, 68 as second order patients, 8 anxiety, 12 very young children (0-5 years), reduction of, 86 17 - 18Asia. See also Taiwan engagement strategies for, 60-61 family structures in, 56-57 age-appropriate, 65, 70-71 Australian Data Linkage System card activity for, 74 (ADLS), 49 health care professionals' roles in, bereavement, death and, 104 preparation for parents, 67 age-appropriate responses to, 96 recommendations and guidelines communication patterns for, by family type, 100 evidence-based interventions for, 78-82 coping skills components of, 78-79



Index

children (cont.) through intervention programs, 86 family communication with, parenting culture and, 44 underestimation of children's cultural contexts, for cancer, 49-54 reactions, 39-40 for African Americans, 53-54 gender of, mixed findings influenced conceptual approaches to, 47-48 by, 10-11 cultural meaning of cancer, 50-54 information sources for, 60-65 in China, 50 child-friendly bibliography, 69, for families, 51-54 72 - 74database management for, 49-50 parents as, 62-65 Australian Data Linkage System, 49 recommendations of, 66 Birth Registrations, 49 international contexts for cancer, Family Connections, 49 policy guidelines for, 54-57 Midwives Notification System, 49 in Saudi Arabia, 55-56 national registries, 49-50 in Taiwan, 56-57 Western Australia Cancer Registry, peer support for, 65 perceptions of cancer, as word, 7 in Finland, 51 preparations for hospital visits, 68-69 information management for, 49-50 Children Lives include Moments of in Iran, 51 Bravery programme, 76 language barriers and, 57 Children of Somatically Ill Parents, 76 in Latin America, 51-53 China, cultural meaning of cancer in, 49 diagnosis stage in, 52 chronic phase, of cancer, 2-3, 29 familism values in, 53 family dynamics as factor in, 52-53 CLIMB programme, 84 communication, within families, 38-41 spiritual values as influence on, 53 children's reactions during, in Malaysia, 53 underestimation of, 39-40 parent's culture as influence on, 57 coping skills influenced by, 38 sensitivity to, recommendations for, 57 visual aids and, 57 for death and bereavement, by family type, 100 cultural meaning of cancer, 50-54 open communication, 39 in China, 50 for families, 51-54 typography of, 40 by women, 39 compassion, 14-15 death, bereavement and compassion fatigue, 116-117 age-appropriate responses to, 96 conflict, within families, 38 communication patterns for, by family marital distress, 38 type, 100 coping skills coping skills for death and bereavement for families, 96-99 for families, 96-99 length of illness as factor, 98-99 length of illness as factor, 98-99 for parents, 96-99 for parents, 96-99 preparations for death, 95 preparations for death, 95 family support programmes, 101 Family Resilience Theory, 101 for emotional impact, 22-23 emotion-focused coping, 22 hospital-based, 101 problem-focused coping, 22 long-term impact of, 102-104 from evidence-based interventions, 86 Adjustment Disorder, 107-110 preference for place of dying, 103 family communication as influence perceptions of, 93-96 on, 38 parental mood as factor in, 36 preparations for, for children and family dynamics and, 36 adolescents, 93-96



Index

| coping skills in, 95 | mixed findings on, 9-11 |
|--------------------------------------|---|
| during palliative care, 94-95, 103 | age factors in, 10-11 |
| special needs after, 107-110 | gender factors in, 10-11 |
| support strategies for, 104-107 | informants in, 10 |
| Can Teen Australia, 105–107 | outcome measures, 11 |
| peer support, 105–106 | for research design, 11 |
| school support, 106 | on social desirability, 11 |
| depression, 12, 86 | timing as factor in, 10 |
| diagnosis stage, 28–29 | for mothers with cancer, 16 |
| adjustment period after, 29 | negative outcomes from, 11-13 |
| crisis phase, 28 | perceptions of cancer, as word, 7 |
| health care professionals and, role | positive incomes from, 13–15 |
| during, 28–29 | career choice through, 14 |
| in Latin America, cultural contexts | compassion as, 14–15 |
| for, 52 | empathy as, 14–15 |
| parenting culture and, 42 | improved relationships, 15 |
| 1 8 | maturity as, 14 |
| emotional fatigue, for health care | post-traumatic growth, 14 |
| professionals, 116 | resilience as, 14–15 |
| emotional impact, on families | Post-Traumatic Stress Disorder as |
| on adolescents, 9, 19–21 | result of, 13 |
| questions about, 25 | previous knowledge of cancer as |
| relationships with professionals, 23 | influence on, 21–22 |
| anxiety from, 12 | on relationships, 13 |
| approaches to, 8 | positive outcomes for, 15 |
| on children | relationships with professionals, |
| questions for, 25 | 23, 23 |
| school-age children (9–11 years), | sadness from, 12–13 |
| 18–19 | Secret Angels game, 24, 24 |
| as second order patients, 8 | sex of child as factor in, 16 |
| very young children (0–5 years), | somatic symptoms of, 13 |
| 17–18 | stress from, 12–13 |
| coping skills for, 22–23 | worry as result of, 12 |
| emotion-focused, 22 | emotional regulation, 86 |
| problem-focused, 22 | emotion-focused coping, 22 |
| depression as result of, 12 | empathy, 14–15 |
| developmental stage as influence on, | end-of-life conflict, within families, |
| 17–21 | 101–102 |
| in adolescents, 19–21 | Family Conflict at the End of Life |
| in mixed findings, 10–11 | scale, 111 |
| in school-age children (9–11 years), | evidence-based interventions, for cancer. |
| 18–19 | See also treasure box intervention |
| in very young children (0–5 years), | activities in, 84–85 |
| 17–18 | by age group, 83 |
| in young children (6–8 years), 18 | for children and adolescents, 78–82 |
| for fathers with cancer, 16 | components of, 78–79 |
| fear as result of, 12 | Children Lives include Moments of |
| health concerns influenced by, 12–13 | Bravery, 76 |
| during illness stage, 15–16 | Children of Somatically Ill Parents, 76 |
| isolation as result of, 13 | CLIMB programme, 84 |
| loss and void as result of, 12–13 | conceptual approach to, 75–78 |
| 1000 and void as result of, 12-13 | conceptual approach to, 75-76 |



Index

evidence-based (cont.) guidance practices for, 45-46 coping skills from, 86 in Latin America, cultural context for delivery mechanisms of, 83-84 cancer influenced by, 52-53 face-to-face, 84 previous cancer history as influence hybrid, 84 on, 35-36 online, 83-84 family interventions, 77 dosage of, 77 Family Resilience Theory, 101 family interventions, 77 family support programmes, 101 FOCUS programme, 80, 81 Family Resilience Theory, 101 for health care professionals, 86-88 hospital-based, 101 love tokens, 89 fathers, with cancer. See also parental materials as part of, 84-85 outcomes from, 85-86 emotional impact of, 16 psychosocial interventions, 76, 79 parenting culture for, 42-43 school-based, 88-89 fear, 12 visualisation exercises, 88 Finland Wonders and Worries programme, cultural context for cancer 80, 82 in. 51 policy guidelines for cancer, 55 face-to-face evidence-based FOCUS programme, 80, 81 interventions, 84 familism values, in Latin American gender. See also sex countries, 53 of child, mixed findings influenced Family Conflict at the End of Life scale, 111 by, 10-11 Family Connections, 49 of ill parent, mixed findings family dynamics influenced by, 10-11 characteristics of family, 35-36 good motherhood standards, 42 well-being of members, 35 gratitude practices, 58 conceptual approach to, 33-34 definition of family, 33 Health and Medicines Act family communication, 38-41 (Sweden), 54 children's reactions during, health care professionals. See also underestimation of, 39-40 self-care coping skills influenced by, 38 challenges for, 117 open communication, 39 during diagnosis stage, 28-29 typography of, 40 emotional fatigue for, 116 by women, 39 in engagement strategies, for children family conflict, 38 and adolescents, 60-61 evidence-based interventions for. marital distress, 38 86-88 family coping skills, 36 communication as influence institutional barriers for, 118 organisational facilitators, 118 on, 38 parental mood as factor in, 36 policy implications for, 118-119 rewards for, 117 family functioning, 33-35 in Family Systems Theory, 34 hospital visits family resilience, 36 death and bereavement interventions model of, 37 through, 98 family structure and, 41-42 preparations for, 68-69 in Asia, 56-57 hospital-based family support parentification behaviours, 41-42 programmes, 101 single-parent households, 41-42 hybrid evidence-based interventions, 84



Index

illness stages. See stages of illness National Cancer Institute (U.S.), 76 information management, cultural National Institute for Health Care context for, 49-50 Excellence (NICE) (U.K.), 55 national registries, 49-50 information sources NICE. See National Institute for Health for children and adolescents, 60-65 child-friendly bibliography, 69, 72-74 Care Excellence parents as, 62-65 Norway, policy guidelines for cancer, 54 recommendations of, 66 international contexts, for cancer policy online evidence-based interventions. guidelines for adolescents, 54-55 83-84 impact of cancer on, 55-57 open communication, 39 in Africa, 57 in Asia, family structures as influence palliative care, death and bereavement on, 56-57 preparations during, 94-95, 103 for children, 54-55 parental cancer. See also emotional impact of cancer on, 55-57 impact in Saudi Arabia, 55-56 conceptual approach to, 3-5 in Taiwan, 56-57 limitations of scope in, 3, 4 conceptual approaches to, 47-48 variables in, 3-4 in Finland, 55 gender of parent, mixed findings legal approaches to, 54-55 influenced by, 10-11 in Norway, 54 methodological approach poverty factors, 47-48 to, 5-6 racism and, 47-48 parentification behaviours, 41-42 social justice issues, 47-48 parenting culture, 42-45 in Sweden, 54-55 conceptual approach to, 33-34 Health and Medicines Act, 54 coping mechanisms in, 44 diagnosis as influence on, 42 in United Kingdom, NICE Guidelines guidance practices for, 45-46 in. 55 Iran, cultural contexts for cancer in, 51 with ill fathers, 42-43 isolation, 13 parental needs in, 43-45 of healthy parent, 44 Latin America, cultural contexts for of ill parent, 44 cancer in, 51-53 for social support, 44-45 diagnosis stage in, 52 role of mothers in, good motherhood familism values in, 53 standards, 42 peer support, for children and family dynamics as factor in, 52-53 adolescents, 65 spiritual values as influence on, 53 for death and bereavement, 105-106 location of death, preferences for, 103 loss and void, 12-13 positive outcomes, during stages of love tokens, 89 illness, 30 post-traumatic growth, from emotional Malaysia, cultural contexts for cancer impact of cancer, 14 in. 53 Post-Traumatic Stress Disorder, 13, 86 marital distress, 38 poverty, cancer policy guidelines Midwives Notification System (MNS), 49 and, international contexts mothers, with cancer. See also parental for, 47-48 problem-focused coping, 22 cancer emotional impact from, 16 ProQOL tool, 121-122 family communication by, 39 psychosocial interventions, 76, 79



quality of life issues, stages of illness as

influence on, 30

Index

72 - 74racism, cancer policy guidelines parents as, 62-65 and, international contexts recommendations of, 66 for, 47-48 parental needs for, 44-45 resilience, of families, 36 by peers, 65 emotional impact as influence on, quality sources, 60-65 in schools, 65-66 Family Resilience Theory, 101 selection of, 61-62 model of, 37 in self-care, for health care professionals, 120 sadness, 12-13 spirituality, in Latin America, cultural Saudi Arabia, policy guidelines for cancer contexts for cancer influenced in, 55-56 bv, 53 schools squeezing exercises, as self-care evidence-based interventions strategy, 120 in, 88-89 stages of illness social support through, 65-66 chronic phase, 2-3, 29 for death and bereavement, 106 diagnosis, 28-29 second order patients, children as, 8 adjustment period after, 29 Secret Angels game, 24 crisis phase, 28 security, sense of, 86 health care professionals and, role self-care, for health care professionals during, 28-29 barriers to, 118 lifetime impacts, 30-31 for burnout, 116-117 psychological adjustment symptoms of, 117 issues, 30-31 quality of life, 30 for compassion fatigue, 116-117 definition of, 114 positive family outcomes, 30 emotional fatigue and, 116 practical guidelines during, 31 organisational facilitators' role stress, 12-13 in, 118 stretching exercises, as self-care planning for, 119-120 strategy, 121 buddy system approach in, 120 Sweden, policy guidelines for cancer in, 54–55 social support as part of, 120 profiles approaches to, 115 Health and Medicines Act, 54 ProQOL tool, 121-122 self-assessment as part of, 114 Taiwan, policy guidelines for cancer in, 56-57 strategies for, 119-120 squeezing exercises, 120 terminal cancer. See also bereavement stretching exercises, 121 conceptual approach to, 91-93 sense of security. See security coping skills sex, emotional impact influenced by, 16 for families, 96-99 single-parent households, family length of illness as factor, 98-99 for parents, 96-99 dynamics in, 41-42 sleep improvement, 86 family conflict and, 101-102 social justice issues, international context family support programmes, 101 for, 47-48 hospital visits and, 98 social support, 65-66 positive outcomes as result of, 96 treasure box intervention, 110 child-oriented, 61

information sources, 60-65

child-friendly bibliography, 69,



Index

United Kingdom (U.K.), cancer policy guidelines, under NICE, 55 United States (U.S.), National Cancer Institute, 76

vision boards, 32 visualisation exercises, 88

Western Australia Cancer Registry (WACR), 49

women. See also mothers communication within families by, 39 good motherhood standards for, 42 Wonders and Worries programme, 80, 82 World Health Organisation, 76 worry, 12

young people. See adolescents