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Psychosocial Interventions in Cancer

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Introduction

Cancer survivors face significant disease- and treatment-related changes that can be distressing and lead to long-term physical and psychosocial dysfunction and quality-of-life deficits. At all points in the cancer experience, from diagnosis to long-term survivorship, there may be physical, emotional, interpersonal, and existential or spiritual difficulties. People vary in their ability to cope with the stressors that occur with diagnosis and treatment and the ongoing challenges of late and long-term treatment effects. Psychological responses range from normal feelings of vulnerability, sadness, and fear to problems that can become disabling, such as clinical levels of depression or anxiety, interpersonal dysfunction, social isolation, and existential or spiritual crisis. Distress may be experienced as a reaction to the disease, disruptions in quality of life, uncertainty about the future, and fears about long-term impairment and risk. Importantly, not all psychological reactions are negative, and many cancer survivors report finding some benefit in their experience such as a finding meaning, new appreciation of life, improved self-esteem and sense of mastery, and closer relationships with loved ones [1].

Psychosocial distress associated with cancer exists on a continuum ranging from normal adjustment issues to clinically significant symptoms that meet full diagnostic criteria for a mental disorder. The National Comprehensive Cancer Network (NCCN) published the first distress screening and management guidelines for patients in the oncology setting in 1997 and were most recently updated in 2019 [2]. These guidelines aim to address that the majority of cancer patients experience some form of distress at some point along the cancer experience [3]. Distress screening enhances the ability of hospitals and cancer centers to identify those in need. Screening alone does not treat distress, however, and referrals and implementation of supportive care resources for those who screen positive for distress are lacking [4–6]. It must be considered that patients in high need may require more than one referral or are best cared for through a multidisci-

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plinary approach, which may be difficult to coordinate through screening measures, such as the NCCN distress screening. Other screening measures, such as the Hospital Anxiety and Depression Scale or the Psychological Distress Inventory, offer alternative methods of capturing and reporting those who may be in most need presenting in the clinic [7]. There are multilevel factors that affect institutional capacity for responding to positive distress screening including the need for multidisciplinary referrals to address identified problems [8]. Other evidence suggests many individuals may refuse to complete distress screeners or refuse additional support regardless of distress, and other screening instruments may be used [9, 10]. Nevertheless, patient-centered care principles highlight the importance of treating the "whole person," and it is critical to identify those in need of support. Evidence-based psychosocial interventions are important for addressing cancer survivors' distress and promoting adaptive coping in the long term.

Importantly, the benchmark for intervening with patients is not the clinical diagnosis of a mental disorder but more often is related to the level of interference or impairment they are experiencing and desire for support. At one end of the spectrum, individuals express "normal" adjustment reactions and experience transient feelings of distress such as anxious thoughts and depressive symptoms. Although there may be some impairment in functional domains, ongoing emotional reactions are not severe enough to significantly impair functioning, and patients demonstrate adequate coping skills and support resources. At the other end of the spectrum, individuals experience symptoms that are severe and frequent enough to meet diagnostic criteria for a debilitating mental health disorder such as major depressive disorder or an anxiety disorder. Between both ends of the continuum lay adjustment disorders and subclinical symptoms of mental health conditions. Up to 52% of cancer patients report high levels of distress, and between 24 and 47% of survivors indicate clinically significant psychiatric disorders [3, 11, 12]. Estimates indicate that during treatment, up to 27% of individuals with cancer report depression and 14% meet diagnostic criteria for current major depressive disorder, and 48% report clinically relevant symptoms of anxiety and 18% meet criteria for an anxiety disorder [13, 14]. Posttreatment cancer survivors experience greater rates of major depressive episodes, severe distress, suicidal ideation, and serious mental illness at up to two times that of their cancer-free counterparts [15]. Other common syndromes include persistent depressive disorder (previously dysthymia) and subsyndromal depression (also called minor depression or subclinical depression). Mental health disorders are often accompanied by upsetting symptoms such as sleep disturbances, fatigue, and pain [16–18]. These symptoms may co-occur and exist in clusters as a mix of psychological, physical, or cognitive symptoms that often present together, such as fatigue, depression, sleep disturbance, and pain which together predict quality of life of patients with cancer [19]. The psychological and emotional reactions to cancer are considered briefly below.

The impact of cancer on psychological and emotional well-being is highly variable and often multifactorial. Cancer site and stage, treatment course, prognostic medical factors, and the burden of side effects and/or long-term physical impact will predict many of the challenges individuals face and are among the strongest predictors of emotional reactions. Psychosocial outcomes also vary among subgroups based on demographics and the occurrence of protective factors such as having a strong support network and well-honed coping skills. For example, depression is more common in younger-aged survivors and in those with poorly controlled pain, physical impairment or discomfort, limited social support, and more advanced-stage disease [20, 21]. Among young adult survivors of cancer (18–38 years old), rates of mental illness are up to four times those of cancer survivors ages 50–64 [15]. Those with a premorbid history of depression or anxiety or who present with current and ongoing symptoms at the time of diagnosis are also at increased risk for experiencing adjustment difficulties and more severe emotional reactions

[20, 22]. Non-cancer stressors, either preexisting or concurrent, may compound cancer-related stress and further overwhelm the survivor and increase supportive care needs.

Despite this, the majority of cancer survivors adjust relatively well. Although the normative reaction to a cancer diagnosis is typically that of alarm and fear and coping with side effects may be quite difficult at times, most patients never meet full diagnostic criteria for a mental health disorder. This should not undermine the need to address emotional difficulties and support needs of cancer survivors. Even mild symptoms of distress can lead to impairment if untreated with clinically significant outcomes. For example, avoidant behaviors may affect cancer treatment through missed medical visits or treatment nonadherence [23, 24]. It is important to highlight the continuum within which emotional well-being and psychological distress occurs and to approach clinical care with this variability in mind.

Psychosocial interventions for cancer survivors generally aim to reduce emotional distress, enhance coping skills, and improve quality of life. Additional aims may include improvements in treatment engagement or adherence, assistance with practical issues, and bolstering health behaviors such as diet and exercise [25]. The design may be for individuals or group- or couples-based. Intervention components typically involve an emotionally supportive context to address fears and anxieties, the provision of information about the disease and treatment and intervention approach, cognitive and behavioral coping strategies, and relaxation training. Psychosocial interventions may be best utilized by targeting the specific needs and stressors of individuals at different levels of psychological functioning and at each phase of the cancer experience.

The goal of this chapter is to review the psychosocial responses of cancer survivors across the cancer continuum, from diagnosis to long-term survivorship, and describe interventions that may be used at each stage of the cancer experience to best meet the emotional and supportive care needs of survivors with a targeted approach.

Psychosocial Responses in Cancer Survivors

Diagnosis

The initial diagnosis of cancer is often a traumatic and distressing experience. Normative emotional reactions include feelings of disbelief, guilt, anger, denial, panic, fear, and despair. Cancers caused by poor health behaviors may be particularly distressing, shameful, or stigmatizing, as is seen among smokers who develop lung cancer. The spectrum of emotional reactions ranges from depressive symptoms to clinically significant symptoms of adjustment disorder or major depressive disorder, categorized by impairing distress. Whether real or perceived, facing the threat of life limiting illness or long-term impairment is a jarring experience. It is very normal for patients to struggle with feelings of uncertainty and fear for the future. Concurrently, decisions about treatment options and preparing for impending procedures, typically within a short time frame, often add to stress levels with little time afforded to patients to adjust and garner resources for support and coping.

Survivors may feel additional distress in anticipation of treatment-related changes and inherent uncertainty about the future including the degree of life disruption and impact on loved ones. For example, young adults often struggle with forced disruptions in educational pursuits and career disruption, which may impact long-term financial well-being and life trajectories. Older individuals may need to depend on the care and support of their children, and these role changes may be distressing, particularly if they worry about being a burden. The social context is critical in determining the emotional impact on patients. This period of time may be more difficult for those who are un-partnered, in an emotionally unsupportive relationship, or who lack an adequate support network. Social isolation is associated with poorer immune function and physical and mental health outcomes across cancer types and stages [26, 27]. Cumulatively, the sudden emotional cascade and anticipated life changes that come with a new cancer diagnosis may be quite stressful and overwhelming for many patients and their loved ones.

Although a cancer diagnosis is naturally quite distressing at first, initial emotional responses are often relatively brief, extending over several days to weeks [28]. Nevertheless, individuals may still benefit from interventions designed to enhance adjustment and coping skills and prepare them for the challenges ahead. Relevant tasks that can be experienced as stressful include disclosure to loved ones and planning for expectable life changes such as time away from work or childcare needs, which may require sharing the news with colleagues and employers, asking for help, and financial planning. Research points to the efficacy of relaxation techniques, education, and skills training in preventing and relieving anxiety and depression and promoting quality of life in newly diagnosed survivors [29, 30]. It is critical to provide newly diagnosed patients information about what to expect based on the medical circumstance and where to find resources if and when difficulties arise. It may also be important to introduce supportive interventions to begin skills building to manage stress and anxiety and prepare for the future.

Treatment Decision and Pretreatment Preparation

With a new diagnosis of cancer comes a cascade of medical decisions and treatment planning for upcoming medical care. It is common for survivors to feel overwhelmed and stressed with treatment decision-making as many will be uninformed about their disease and treatment options and may have difficulty understanding guidelines or risk/benefit ratios, particularly when there is uncertainty about treatment efficacy or risk of complication. In some instances, treatment options may be relatively equivalent, and the decision, therefore, should depend on individual values, priorities, and preferences in relation to expected posttreatment side effects and quality of life impact. It can be difficult to predict the impact late and long-term effects will have on quality of life, and many survivors underestimate the degree to which they are bothered by side effects when they occur [31]. The challenges of treatment decision-making and preparation may be exacerbated for those with inadequate medical care or poor communication with their oncology team, particularly for subgroups with limited language proficiency and poor health literacy. Internet searches are the most common method for finding information related to cancer for oneself or a loved one and can lead to misinformation [32]. Whether sought out or unsolicited, survivors often hear anecdotal cancer information from social networks that can also be misleading and confusing.

Targets of intervention during the pretreatment time period focus on providing support for treatment decision-making and treatment preparedness (e.g., stress management and relaxation techniques prior to surgery). Interventions to assist in the treatment decision-making typically involve decision aids with the objective that patients will make informed, values-based decisions with careful consideration of risk-benefit tradeoffs (pros/cons of treatment options) and consistency with personal priorities and goals [33, 34]. Decision aids may be used to guide decisions when there is equipoise among treatment options such as the case with localized prostate cancer deciding among active surveillance, radical prostatectomy, or radiotherapy or breast cancer patients determining surgical and reconstruction options [35, 36]. Alternatively, decision aids may be used to support decisions about concomitant care such as young adults considering fertility preservation prior to gonadotoxic treatments [37, 38].

Psychosocial interventions designed to be delivered prior to the start of treatment have mostly been conducted among breast and prostate cancer survivors prior to the start of chemotherapy or surgery and typically involve relaxation training (e.g., progressive muscle relaxation techniques, guided imagery) and stress management to prepare survivors for their treatment(s). Those designed to prepare individuals for cancer treatment have been shown to be effective in reducing anxiety and depression and improving satisfaction with cancer care, with evidence suggesting that even brief interventions (e.g., one session, 15–20 min long, remote delivery) may be beneficial [28, 29, 39–41]. Reviews of the literature have suggested positive effects on disease-specific and general quality of life, including reduced posttreatment side effects such as nausea and vomiting and less psychological distress [20].

Active Treatment

The active treatment phase poses additional stressors that often impact psychosocial well-being and quality of life. Treatments almost inevitably have some side effects that may include one or a combination of symptoms such as pain, nausea and vomiting, insomnia, fatigue, bodily changes or disfigurement, urinary or bowel incontinence, and sexual dysfunction. The sequelae of side effects vary between early and more advanced-stage disease and extent of treatment received. Advances in screening and early detection have led to more individuals diagnosed with early-stage disease with treatments that have fewer or less intense side effects. Survivors living with advanced disease face additional physical (e.g., pain, functional limitations) and emotional (e.g., fear of dying, end-of-life issues) consequences that further impact quality of life. Additional stressors during this time may include negotiating changes in occupational and family roles, managing household and childcare responsibilities, worrying about finances, and interference with educational or career advancement. Even for those who do not experience chronic or debilitating side effects, significant change in functioning or altered independence may still be highly distressing, particularly if survivors experience changes that threaten identity and sense of self. There may be downstream physiological changes as well including decreased immune function associated with negative psychosocial outcomes and cognitive function [42].

Some of the most common concerns reported by cancer survivors during treatment are related to feelings of uncertainty and a diminished sense of control and predictability. Again, the specific nature of these concerns often depends on medical factors including disease stage and treatment course, and the general impact on daily living and expectations about the future. Uncertainty may be related to treatment efficacy or anticipated side effects and, particularly among those with more advanced-stage disease or with poor prognostic indicators, include worries about long-term quality of life and fears about death and dying. Undergoing medical treatments involves a certain degree of losing control and autonomy over one’s body and can create a sense of feeling “medicalized” or disconnected from the body. It may lead to a feeling of reduced autonomy and self-efficacy related to their physical condition and health outcomes, particularly if they feel uninvolved in decision-making about treatments and medical care. Lack of social support or feel disconnected from social networks due to illness contributes to psychosocial distress. Many patients experience a loss of daily routines and disrupted work and social activities during treatment. They may be limited in social activities that can lead to reduced time spent with loved ones, distancing of relationships, and social isolation. High levels of cancer-related distress are associated with interpersonal dysfunction including reduced support-seeking behaviors and lowered perceptions of support. For example, treatment for head and neck cancer often results in facial disfigurement and functional limitations (e.g., problems with speech, breathing, and/or eating) that are associated with embarrassment, lowered self-esteem, body image concerns, and social isolation [30, 31]. Cancer-related changes can disrupt interpersonal relationships and lead to inadequate levels of social support, which may continue posttreatment.

Psychosocial interventions in cancer survivors undergoing treatment have shown positive effects on physical and emotional well-being. Evidence suggests that relaxation training, psychoeducation, supportive or supportive-expressive therapy, and cognitive behavioral therapy have all been found to be effective in preventing or relieving anxiety and depression; evidence is strongest for relaxation training in reducing anxiety [29]. This is reviewed in more detail in later sections of this chapter.

Advanced-Stage Disease

As suggested, individuals experiencing progressing or advanced cancer with poorer treatment outcomes report the greatest levels of psychological distress and decrements in quality of life. Aside from the emotional difficulty of coping with end-of-life concerns, advanced-stage cancer survivors often experience more significant physical side effects, such as pain, nausea and vomiting, urinary incontinence, fatigue and difficulties breathing, eating and/or swallowing, and declining functional abilities that lead to further decreases in quality of life and emotional well-being. As the degree of debilitation advances and patients are unable to manage their self-care, the caregiver burden may become too great and discussions about assisted care may be required. For those who are in the hospital, additional concerns include bed sores, difficulty sleeping, disruptive or unfamiliar environments (e.g., nurses checking in periodically through the night), as well as the added stress of spending time with and interacting with family members and loved ones outside the comfort of one's home or familiar environment. Stresses are compounded by the need to negotiate difficult choices around end-of-life treatments and care, coping with anticipatory grief, as well as the emotional reactions of children and other family members, and concern about the patient's legacy in both psychological and practical terms. At the end of life, as physical well-being declines, patients may experience a more profound loss of control over their body and reduced dignity and self-esteem. If care is transferred to an inpatient medical setting for an extended period of time, survivors may experience a loss of relationships, both with friends and family as well as spiritual relationships, that lead to a perceived loss of support and greater social isolation [43, 44].

Existential fears will naturally occur among patients coping with progressive disease and anticipated death that further challenge psychological well-being and interpersonal functioning at the end of life. Aspects of existential and spiritual concerns refer to survivors' sense of peace, purpose and connection to others, and their beliefs about the meaning of life. Religiosity and strong spiritual beliefs can be protective in guiding patients toward greater acceptance about the eventuality of death and beliefs about an afterlife, or, alternatively, the experience may cause a spiritual crisis and increased distress (e.g., feeling abandoned by one's God). Those who experience significant threats to their existential and spiritual well-being are at increased risk for feelings of despair and hopelessness, feeling like a burden to others, loss of their sense of dignity and will to live and desire for death [44, 45]. They may feel overwhelmed by suffering and unable to cope with the situation. Research suggests that "feeling like a burden to others" is significantly associated with depression, hopelessness, greater fatigue, and lower quality of life [45]. Alternatively, those who are able to find a sense of meaning and peace of mind in their cancer experience may be better equipped for handling end-of-life concerns, adjusting to changes, and optimizing quality of life to the extent possible. The degree to which survivors are able to cope with existential and spiritual concerns is related to cancer-related adjustment overall and perceptions of total health and well-being. Interventions tailored for terminal cancer patients must address the realistic concerns that occur at this time including fears about disease progression, death, and dying, progressing functional limitations, and worrying about loved ones; and focus on skills building for relaxation, coping with cancer worries, and activity pacing [22, 46].

Posttreatment Survivorship

As the number of cancer survivors continues to grow, there is increasing recognition of the need to manage their unique medical and psychosocial needs within a long-term care approach. Posttreatment cancer survivorship is now characterized as a chronic condition requiring specific and targeted efforts to address the long-term issues and late effects survivors experience [47]. This paradigm is a departure from how cancer care was historically conceptualized, as an acute and time-limited course of treatment that is managed by oncology specialists. In contrast, due to factors that are unique to cancer care, individualized patient profiles, long-term and late effects, and need for ongoing surveillance, it must be recognized that survivors face a number of distinct psychosocial challenges that persist well past the acute phase of disease and active treatment.

In the posttreatment survivorship phase, psychological distress may result from a number of cancer-specific concerns that persist well past the acute phases of illness, irrespective of being in remission or "cured" of disease. Negotiating the transition back to "normal" life is often a primary challenge. This involves resuming daily activities and relationships, including intimate and sexual relationships, discussing changes in life plans, implementing health behavior changes, coping with long-standing or permanent disease and treatment effects, and managing fears about disease recurrence. For young adult survivors, cancer often interrupts educational and career pursuits, and survivors may feel derailed from their expected life trajectory. This transition involves coming to an understanding of how cancer has affected personal and interpersonal life narratives such as finding meaning in the cancer experience, finding closure, and negotiating any changes in existential beliefs and life purpose. Many survivors need to actively integrate this new aspect of their identity as a "cancer survivor" into their self-concept while learning to accept changes that persist beyond the end of treatment (e.g., cognitive declines, new outlook on life) and adjusting to the prospect that they may be unable to return to their precancer "normal" self. Fear of recurrence is one of the universal psychosocial challenges at this time and is identified as a root cause of posttreatment psychological distress [48]. The challenges survivors face may be quite personal, and others in their social network may fail to recognize the continued difficulties they experience. Some may expect survivors to "go back to normal" after cancer and fail to recognize continued support needs. At high levels of distress, survivors may avoid medical care or resist long-term surveillance or be unmotivated to comply with risk-reduction behaviors (e.g., physical activity, smoking cessation) as a way of avoiding reminders of cancer and to manage distress.

Sexual health, in particular, is often cited as a particularly challenging domain of survivorship. Without intervention, sexual side effects often persist or worsen in survivorship and can lead to significant impairment in personal well-being and relationships. Despite reporting posttreatment levels of vitality, physical well-being, and levels of general quality of life that are comparable to or above age-matched normative levels, men often indicate distress related to sexual dysfunction [49, 50]. Functional impairment and body image concerns all contribute to sexual impairment. For younger survivors, treatment-related infertility risk is cited as among the most distressing aspects of cancer survivorship with long-term effects on psychosocial well-being, particularly if there are barriers and challenges to achieving family-building goals.

There is a clear rationale for continued psychosocial support after the active treatment. Psychological distress should be assessed, monitored, and treated promptly at all stages of cancer, including the survivorship phases.

Distress management in the survivorship phase of cancer care:

- Need for routine screening to assess psychological distress and psychosocial needs.
- Screening should identify the level and nature of the distress.
- Referrals for psychosocial interventions should be specific to the survivorship needs.

Benefit Finding Importantly, many cancer survivors report beneficial effects of cancer and psychological growth as well. It is a common finding that survivors feel stronger and more able to handle future life challenges after having survived their cancer experience. Cancer caregivers also report benefit finding in relation to meaningful experiences created while caring for their loved ones [42]. For patients, positive psychological consequences reported in the literature include better interpersonal relationships, including quality of marital relationships, changes in values and priorities, greater appreciation of life, and improved quality of life [51–53]. Such positive changes are associated with altered attitudes about personal health and death and may occur up to months or years after diagnosis and treatment. Notably, both positive and negative effects of cancer may – and often do – occur, representing multiple domains of physical and emotional well-being and quality of life [51, 52], suggesting that psychological assessment and intervention may be required even among those who indicate some benefit or positive outcome of cancer.

Critical Transition Period

The transition from active treatment to the posttreatment phase of the cancer continuum is often a time of change and uncertainty for many cancer survivors. The first few months may be filled with mixed emotions. For those that are disease free, there is a relief to be finished with the demands of treatment and welcome the resolution of side effects. At the same time, survivors may feel uneasy with the decreased contact with their providers and safety net of the medical team. It is common to have feelings of hesitation in celebrating being cancer-free. As individuals move from frequent to more infrequent medical visits, they no longer receive the reassurance of frequent check-ins with providers and the reassurance those interactions provide and as a result feel an increased sense of vulnerability. Likewise, there may be great uncertainty about recommended health behaviors (e.g., "Now what do I do?"). Settling into a "new normal" can be challenging and stressful, particularly if late/long-term effects are debilitating or cause functional limitations. Close relationships may be affected. Partners may adjust in different ways and that incongruence is associated with increased distress in both survivors and their partners and cause interpersonal dysfunction. Unrealistic expectations for physical recovery, whether self-imposed or received from others, may exacerbate adjustment difficulties and lead to disappointment and distress. Friends and family members may expect that survivors will be able to resume all of their activities at precancer levels of functioning once treatment is over. Survivors may also expect this from themselves and may be surprised and distressed by physical and emotional limitations following treatment.

Rationale for posttreatment psychosocial assessment and referral:

- Provides opportunity for education and early intervention
- Extends continuum for cancer care
- Facilitates reentry transition
- Facilitates referral for specialized survivorship services

Thus, the critical transition from active treatment to posttreatment survivorship is a unique time period for survivors characterized by paradoxical feelings of both positive and negative emotional reactions. Interventions that have targeted survivors immediately following the end of primary treatment have suggested that relatively simple interventions may help to reduce common adjustment difficulties. These have included videotape interventions depicting issues related to reentry transitions and one-time individual sessions with a cancer educator to prepare and set realistic expectations [29, 54].

Short-Term Survivorship (<1-Year Posttreatment)

In the first year following treatment, many survivors feel "lost in transition." The transition from "sick role" to "well role" is frequently more difficult than survivors expect and navigating the practical issues related to reentry into social and professional networks can be difficult. Many of the physical and emotional difficulties noted may become more apparent as survivors take on more and more of their precancer activities and responsibilities. For example, cognitive changes (e.g., attention or memory problems; "chemo brain") may become more distressing if they interfere with work-related activities and job performance. The emotional aftermath of the cancer experience may only begin to sink in after some time has passed, and many survivors may struggle with a new onset of fears and worries akin to post-traumatic stress. While some may meet full diagnostic criteria for a post-traumatic stress disorder, many more will experience subclinical levels of symptoms that still warrant attention.

Although many studies have described the quality of life of cancer survivors in the first year following primary treatment, this research has largely focused on a few cancers (i.e., breast and prostate), and generalizations to other cancer types that involve different treatment regimens are limited. As treatments are constantly evolving, becoming more complex and, at times, more toxic, caution should also be taken regarding interpretation and applicability of older reports. Nevertheless, there have been many psychosocial interventions targeting this stage of the cancer experience. Interventions typically aim to increase physical and emotional well-being and quality of life by providing psychoeducation related to the expected occurrence and time course of late and long-term effects, improving coping and stress management, and increasing social support.

Aftereffects of Cancer

Aftereffects refer to any long-term or late effects of cancer and its treatment and may range from very mild to serious in terms of their effects on physical and emotional well-being and quality of life (see Table 10.1) [55]. The occurrence of aftereffects and how long they last is often difficult to predict and varies across disease and treatment types and relevant individual characteristics. Long-term and late effects impact a range of physical and emotional domains and may have practical implications for survivors related to accomplishing day-to-day life activities, employment and job performance, and obtaining or maintaining health insurance [55]. Common long-term and late effects are listed in Table 10.2.

Table 10.1 Aftereffects of cancer

IOM Report: Defining Long-Term and Late Effects of Cancer Treatment
Long-term effects refer to any side effects or complications of treatment that begin during treatment and continue beyond the end of treatment; also known as persistent effects
Late effects refer specifically to unrecognized toxicities that are absent or subclinical at the end of treatment and become manifest later because of any of the following factors: developmental processes, the failure of compensatory mechanisms with the passage of time, or organ senescence. Late effects may appear months to years after the completion of treatment

From Aziz and Rowland (2003) [55]

Table 10.2 Long-term and late effects of cancer

Aftereffects of surgery include
Scarring at the incision site and internally
Lymphedema or swelling of the arms or legs
Problems with movement or activity
Nutritional problems if part of the bowel is removed
Cognitive problems such as memory loss and difficulty concentration
Changes in sexual function and fertility
Pain that may be acute (sudden) long-term or chronic
Emotional effects that may be related to feeling self-conscious about physical changes
Aftereffects of chemotherapy include
Fatigue
Sexual problems
Early or premature menopause
Infertility
Reduced lung capacity with difficulty breathing
Kidney and urinary problems
Neuropathy or numbness, tingling and other sensations in certain areas of the body, especially the hands and feet
Muscle weakness
Cognitive problems such as memory loss or inability to concentrate
Osteoporosis
Changes in texture and appearance of hair and nails
Secondary cancers
Aftereffects of radiation include
Cataracts, if treated near the eyes, cranial-spinal or if given total body irradiation (TBI)
Permanent hair loss if the scalp is radiated over certain dose levels
Dental decay, tooth loss, receding gums if radiated near the mouth
Loss of tears and the ability to produce saliva if lacrimal or salivary glands in the face are radiated or there has been TBI
Problems with thyroid and adrenal glands if the neck is radiated
Slowed or halted bone growth in children if bone is radiated
Effects on the pituitary gland and multiple hormonal effects if the hypothalamic-pituitary region is radiated

(continued)

Table 10.2 (continued)

Decreased range of motion in the treated area
Skin sensitivity to sun exposure in area of skin that is radiated
Problems with the bowel system if the abdomen is radiated
Secondary cancers in the areas radiated
Infertility, if ovaries, testes, cranial-spinal area or TBI is directly radiated
Emotional aftereffects following cancer treatment may include
Anger
Sadness, depression, or loneliness
Anxiety
Post-traumatic stress
Health worries and fear of recurrence
Sense of loss for what might have been
Uncertainty and vulnerability (e.g., "my body let me down")
Uncertainty about the future; feeling unable to plan for the future
Concerns about pain, fatigue, or physical side effects
Concerns about body image
Concerns about the future or having a new orientation to time and future
Existential or spiritual concerns (e.g., "Why me?"; "Why now?")
Concerns about death and dying
Search for meaning and purpose; appreciation of life
Social aftereffects may include
Loss of support; isolation
Alienation or stigma
Altered social relationships, including intimate relationships and those with family members, friends, and peers
Comparisons with peers or other cancer survivors
Practical aftereffects may include
Job performance; difficulty working due to physical or emotional aftereffects
Problems getting health or life insurance coverage
Challenges communicating concerns to your healthcare team
Financial stressors
Employment discrimination

- *Long-term effects* develop during treatment and are persistent or chronic side effects that continue for months or even years past the end of treatment. Common long-term effects include physical (e.g., anemia, fatigue, and neuropathy) and emotional (e.g., depressive symptoms) domains of well-being. Many long-term effects improve or resolve with time, whereas others are permanent such as limb loss, muscular weakness, or nerve damage. The prevalence of long-term effects is associated with cancer and treatment type and is influenced by the health and well-being of the individual including premorbid physical and psychological condition.
- *Late effects* refer to any disease- or treatment-related difficulties that are absent or subclinical at the end of treatment but manifest anywhere from months to years later. The increasing complexity of treatment regimens has led to increased prevalence of late effects, which are often dose and modality specific. The increased risk of a second cancer is the most life-threatening late effect, but other disabling conditions occur and need to be monitored for and addressed through medical and psychosocial interventions. Other common late effects include chronic fatigue and neuropathy, cognitive dysfunction, and declines in cardiovascular health [56, 57]. Female cancer survivors may experience premature menopause, and both male and female survivors may experience infertility.

The risk of long-term and late effects depends on the tissue exposed as well as the age and health condition of the patient at the time of treatment [56]. Many older survivors have comorbid medical conditions that may exacerbate treatment-related effects or complicate recovery of premorbid functioning. Tissues at risk for late toxicity include bone/soft tissues, cardiovascular, dental, endocrine, gastrointestinal, hepatic, hematological, immune system, neurocognitive, and nervous system tissue [55–57]. There is an ongoing need to monitor for and prevent late effects and promote healthy lifestyles. Some aftereffects may be expected given the nature of disease and treatment; brain and spine tumors, for example, increase the risk of neurologic deficits [58]; survivors of head and neck cancer are at increased risk for impaired eating, communication, and musculoskeletal functions of the neck and shoulder [59]; individuals with bone cancers are more likely to experience mobility problems due to amputations or limb-sparing procedures [60]; and gonadotoxic therapies (e.g., alkylating chemotherapy, surgery or radiation affecting reproductive organs or hormone regulation) will impact fertility [61]. Beyond general predictions, the degree of risk of late/long-term effects can be difficult to calculate. Many of the aftereffects mentioned in this section extend well into long-term survivorship phases (>5 years post-treatment) [47].

Aftereffects of cancer treatment have the capacity to impact all domains of life including physical/medical, psychological, social, existential, and spiritual aspects of identity and well-being. Some aftereffects may be easily identified because they are visible or have direct effects on function and well-being and are well known and researched. Other effects, however, can be subtle and not readily apparent to the untrained observer (e.g., postural changes due to osteoporosis) or are not directly observable and only detectable through diagnostic testing (e.g., infertility, hypothyroidism). Likewise, emotional difficulties are often difficult to pinpoint and may go unrecognized or be misunderstood by survivors or by their loved ones. Important considerations in dealing with aftereffects of cancer treatment, particularly with respect to emotional and psychological effects, include premorbid mental health functioning, personal and interpersonal resources, and coping strategies. Psychosocial interventions in the first year after treatment typically address concerns related to survivorship transition and coping with residual side effects of treatment and research suggests that participation is associated with a number of benefits to physical and emotional well-being.

Long-Term Survivorship (>5 Years Posttreatment)

Prolonged challenges associated with the cancer experience and permanent impairment in functioning or well-being may manifest as new or exacerbated triggers of distress and dysfunction even years after the end of treatment [62]. For example, unresolved sexual dysfunction may ware on relationships over time or lead to dysfunctional patterns of interaction within couples that undermine intimacy and shared quality of life. Infertility distress may increase among young adult survivors as they approach the age of reproduction and desired family building [63]. Poor overall health and ongoing physical problems may be difficult to cope with in the long-term and lead to practical challenges affecting daily life and life planning (e.g., ability to work and job performance, problems with health insurance). Evidence suggests that despite the adoption of healthy behavior changes after diagnosis and at the end of active treatment, many longer-term survivors do not maintain behavior changes and resume unhealthy lifestyles that were present before cancer (e.g., smoking, being sedentary, being overweight or obese). Common long-term survivorship difficulties are listed in Table 10.3.

While many survivors may be able to adjust to aftereffects and manage lingering fears and concerns with time, others may find that they feel "stuck" and cope strategies are proving ineffective. This requires ongoing monitoring and interventions designed to target the specific sources of distress for survivors coping with lingering cancer effects including both physical and psychosocial areas of functioning. Some survivors may need coping skills to deal with acute but intermit-

Table 10.3 Long-term survivorship difficulties

Physical and psychosocial challenges of long-term survivorship
Adjustment to physical compromise, health worries, and sense of loss for what might have been
Body image concerns
Long-term and late effects of treatment such as fatigue and cognitive difficulties
Increased risk of poor overall health and health-related complications of treatment
Alterations in social support and perceived loss of support from loved ones as well as cancer care medical team
Interpersonal disruption and social isolation
Sexuality and fertility issues and related effects on intimate relationship functioning
Stigma of cancers associated with risk behaviors such as smoking and alcohol consumption
Fear of recurrence and concerns about future and death
Uncertainty and heightened sense of vulnerability
Existential and spiritual issues
Employment and insurance problems

tent experiences associated with cancer such as managing anxiety with annual surveillance tests. Many of the interventions developed for long-term survivors target lifestyle behavior modification to promote healthy behavior changes. Results suggest that dietary and exercise interventions are effective [64, 65], though dissemination of interventions can be difficult as survivors become more removed from cancer care [66]. Not surprisingly, home-based interventions delivered remotely and via digital platforms help to overcome barriers and promote adaptive changes in this vulnerable population of survivors.

Psychosocial Interventions in Cancer

Targets of Interventions

As a cancer diagnosis and its treatment pose significant short- and long-term challenges for survivors and their loved ones, psychosocial interventions that attempt to minimize the negative impact and promote positive adjustment and well-being are increasingly common. Interventions typically aim to improve adjustment and well-being by:

- Guiding treatment decisions and preparation
- Teaching adaptive coping skills
- Improving support-seeking behaviors and reducing social isolation
- Addressing maladaptive cognitions
- Improving communication with partners, loved ones, and providers
- Promoting adherence to recommendations and improving healthy lifestyle behaviors

Psychosocial interventions typically aim to improve adjustment and well-being through the provision of information and acquisition of intra- and interpersonal skills building. The model in Fig. 10.1 proposes that cancer survivors benefit from interventions that are tailored to their individual needs and presenting problems. For example, teaching anxiety reduction skills can provide a way to reduce anxiety, tension, and other forms of stress responses and thus help the survivor achieve a sense of mastery over disease-related

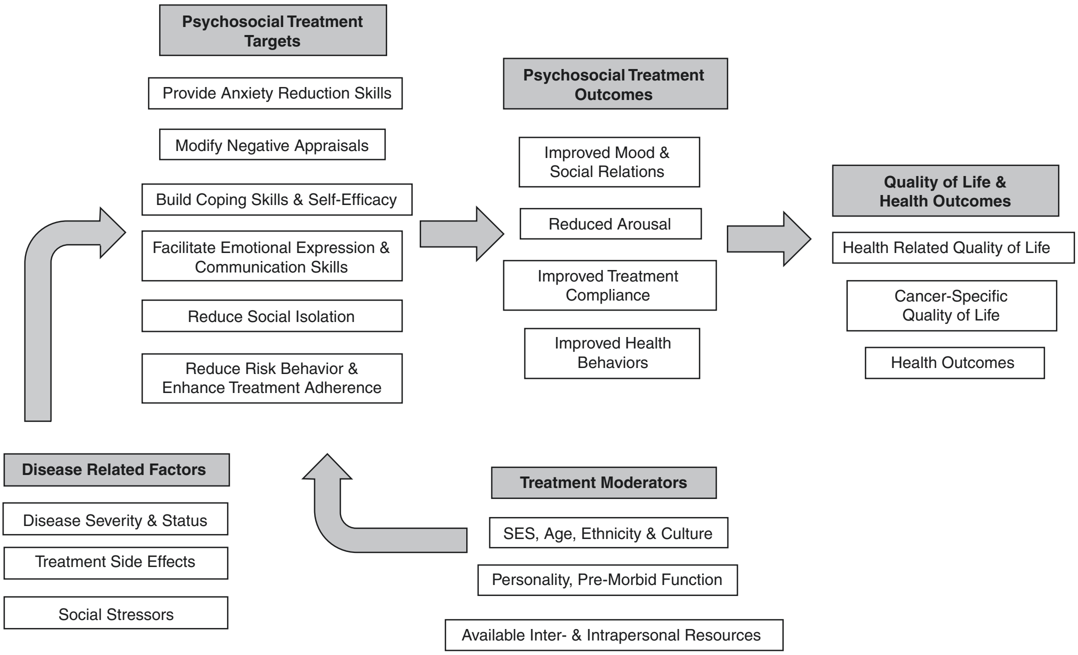

Fig. 10.1 Conceptual model of psychosocial treatment interventions

and general stressors. The use of cognitive restructuring techniques can help survivors identify links between thoughts, emotions, and somatic sensations or physiologic response and increase ability to identify and change maladaptive thought patterns and unhealthy effects on behavior. Participants in these interventions can also benefit from techniques that challenge ineffective or damaging cognitive, behavioral, and interpersonal coping strategies by increasing awareness of the use and consequences of ineffective coping strategies and patterns of behavior that do not result in desired outcomes. Therefore, attention is given to replacing inefficient and indirect ways of dealing with stressors with more effective coping including emotion and problem-focused strategies while increasing survivors' ability to adaptively express both positive and negative emotions and access supportive resources. These intervention models promote identifying and utilizing social support and providing self-management skills. Communication skills are also targeted, particularly those specific to interacting with healthcare professionals and communicating concerns and needs with spouses/partners, family, and friends. When testing psychosocial interventions, outcome measures often include a range of physical and emotional health indices as well as disease-specific and general quality of life. Another important target of intervention is the promotion of healthy lifestyle behavior changes such as diet, exercise, and smoking cessation.

Importance of health promotion following cancer treatment [66, 67]:

- Engaging in health promoting behaviors may improve health outcomes and decrease morbidity and mortality (e.g., tobacco and alcohol cessation, nutrition and diet, exercise, sun protection, cancer screening and prevention, medical surveillance).
- Engaging in health-promoting behaviors can empower active partnership with healthcare providers and may enhance perceived control over health outcomes (reference).

Fear of cancer recurrence is one of the most common occurrences and significant source of distress for cancer survivors. Psychosocial interventions targeting fear of recurrence have been shown to be efficacious, particularly those based in a cognitive behavioral framework [68]. Those shown to be most effective focus on cognitive processes such as worry, rumination, and attentional bias, rather than the content of thoughts, with the goal of altering the way in which individuals relate to their inner experiences. These interventions may be delivered in individual or group formats.

Interventions that target existential and spiritual concerns and end-of-life fears typically focus on issues of control and autonomy, identifying sources of dignity and meaning, addressing relationships challenges, and fostering acceptance and peace [44]. The goals of these interventions are largely the same as those of other interventions, aiming to improve adjustment and coping with benefit to quality of life; though physical outcomes are usually less of a focus than at other stages of the cancer experience [69, 70]. Outcome measures include assessment of self-esteem, purpose in life, optimism, and hope for the future [70]. A literature review of existential and spiritual interventions indicated that the majority of the outcome measures assessed either improved or remained stable in intervention groups and declined in control groups [45]. It appears that psychosocial interventions that target existential and spiritual concerns may be quite important for maintaining emotional well-being and optimizing quality of life even at end-of-life stages [45, 70], with limited evidence suggesting utility in improving physical outcomes [45, 69].

Finally, given the interpersonal nature of cancer, couple-based interventions have been developed with the goal of assisting dyadic processes that promote adjustment to cancer-related changes while avoiding or minimizing individual distress (patients' and partners') and relationship dysfunction. Interventions may either be at the individual- or couple-level. Individual-level interventions that include both members of the couple target individual adjustment and well-being based on the logic that a couple will adjust to cancer most effectively if each partner adjusts well [71]. Partner-assisted interventions are ones in which the goal is to teach skills to both partners to help the person with cancer adjust and cope effectively, and often the partner's role is that of a supporter [72]. Alternatively, couple-level interventions identify relationship functioning as the primary therapeutic focus and target couple-level issues and skills such as problem-solving and effective communication as the means by which individual-level adjustment is enhanced. Intervention material typically addresses cancer-related problems as well as positive relationship functioning in general. A common target of intervention for couples addresses the sexual problems that occur with disease and treatment experiences and rebuilding intimacy. The ways in which couples engage in relationship maintenance strategies (e.g., positivity, openness, assurance) after a diagnosis of cancer impact psychological and relational adjustment over time [71, 73–75], and interventions aim to leverage couples' strengths while teaching adaptive personal and interpersonal coping strategies.

Types of Interventions

There are many different types of interventions developed for cancer survivors, but common therapy components typically include an emotionally supportive context and one or a combination of education, emotional processing, skills building (e.g., to improve decision-making, coping, or communication), stress management, and relaxation training. Interventions provide an opportunity to gain knowledge about the disease and its treatment, address fears and anxieties, learn coping strategies, and, if in a group context, an opportunity to meet peers and share experiential knowledge. Benefits of psychosocial interventions are achieved through a number of therapeutic techniques based on theoretical models of stress and coping, psychological well-being, and health behavior change [28, 76, 77]. There is strong evidence to support cognitive behavioral interventions across the cancer continuum, whereby coping skills are learned from better awareness of the interrelationships among thoughts, feelings, and behaviors [78, 79]. These benefits in coping have been identified as a mechanism of intervention effects on quality of life [80]. Mindfulness-based interventions have increased in popularity and also promote better awareness of the connection between mind and body (thoughts and behaviors) and foster skills to increase control over physiologic responses and relaxation such as through meditation or guided imagery [81].

Interventions range in terms of the degree of structure and adherence to manualized or instructional approaches. Supportive interventions, often group-based, provide survivors with the opportunity to acknowledge and discuss their challenges to other survivors with similar experiences. Therapeutic processes by which participants derive benefit include self-disclosure and receiving support and validation, information exchange, and reducing social isolation [20]. Many survivors also derive esteem by participating in groups and providing support to others. Psychoeducational interventions build on this but tend to be more structured in nature, often focusing on cognitive and behavioral techniques to facilitate adjustment and skills building to foster adaptive coping and a greater sense of control over the illness experience [28, 77]. Participants are typically provided with information pertinent to their disease and its treatment and work toward building acceptance of and adjustment to cancer-related changes. Cognitive behavioral approaches emphasize skill acquisition and behavioral change through goal setting, self-monitoring, coping skills, and social skills training [28, 82]. Consensus about the efficacy of cognitive and behavioral techniques or psychoeducational methods suggests positive effects on a range of physical and emotional well-being outcomes (e.g., fatigue, pain, anxiety, depression, and general cancer distress) [17, 83–85]. Some evidence suggests that cancer survivors may benefit more from structured interventions than purely supportive ones. This may be due to the acquisition of new skills with which survivors can broadly apply to individual stressors specific to their experience and continue after the intervention has ended (e.g., cognitive restructuring, stress management, relaxation techniques) [82].

Cognitive behavioral approaches have also been combined with relaxation training and stress management techniques. Research has shown positive outcomes of a manualized cognitive behavioral stress management (CBSM) group intervention developed and tailored to meet the specific needs of several medical populations, including breast cancer [86–95], ovarian cancer [96], and localized [97–99] and advanced prostate cancer [100–104]. The intervention consists of 10 weekly group meetings that include a 90-min didactic portion and 30 min of relaxation training. Participants are taught a variety of cognitive-behavioral stress management techniques, including identification of distorted thoughts, rational thought replacement, effective coping, anger management, assertiveness training, and development of social support. Information specific to disease physiology, diagnosis, treatment, and side effects is also provided. Participants also learn and practice a variety of relaxation techniques, including progressive muscle relaxation (PMR), guided imagery, meditation, and diaphragmatic breathing, and are encouraged to practice the techniques on a daily basis. The concepts and techniques introduced in each session build upon information covered in prior sessions and are reinforced through group discussions, exercises (e.g., role-plays), and weekly homework assignments. Discussions are tailored to address the specific needs and concerns of survivors. For example, among men with prostate cancer, the intervention aims to provide an opportunity to help men accept a lowered or lack of physiologic response, normalize feelings of anxiety or depression surrounding a perceived loss of male identity, reframe intrusive or distorted thoughts of disappointment or inadequacy, and teach adaptive coping strategies to effectively communicate with sexual partners and adjust to altered sexual patterns [51, 98, 99, 105].

Individual Support and Self-Administered Interventions

Individual interventions include any form of therapy, counseling, or support that is delivered on a one-to-one basis. This may involve therapy or counseling with a qualified professional or volunteer-based support from another survivor (i.e., peer-based programs) or other types of volunteer. Psychotherapy with a professional therapist or counselor offers an opportunity to provide more attention and individualized support than group therapy, and therapeutic efforts may be targeted to the specific needs of the individual. This may be particularly important for survivors who indicate clinically significant levels of distress or meet diagnostic criteria for a mental health disorder, or in cases in which a group context provokes symptoms of distress or unwillingness to disclose information to group participants. The disadvantages, of course, include the added time and resources that individual therapy requires. Peer-based interventions may offer an alternative. It has been reported that peer support helps to increase knowledge about the cancer experience and possible coping strategies, decrease patient's sense of isolation, and provide a sense of hope to cancer survivors [106]. With regard to peer-based programs specifically, participants have indicated positive feelings toward having an opportunity to speak with someone who has shared similar experiences and seeing someone who has survived cancer [106]. In fact, among younger-aged survivors, meeting peers with similar cancer experiences is ranked as among the most important survivorship support needs [107]. There is limited empirical evidence supporting the effectiveness of volunteer-based support programs, and few well-designed randomized-controlled trials have been conducted. Although this may offer a cost-effective alternative to individual psychotherapy, disadvantages of peer-based programs include the lack of formal training of the volunteer support providers; the success of peer-based interventions may depend on their training and supervision.

Peer-based interventions represent an effort to increase the availability of psychosocial interventions by reducing costs and required resources. This may also be achieved through self-administered interventions. Self-administered interventions provide survivors with information to increase their knowledge of effective therapeutic techniques and to develop skills independently to facilitate adjustment and well-being. For example, the effect of a patient self-administered stress management intervention (SSMT) was compared to a professionally administered stress management intervention (PSMT) and a usual care control (UC) condition among cancer survivors undergoing chemotherapy [108]. The PSMT condition consisted of a single 60-min session conducted by a mental health professional in which discussion included psychoeducation regarding stress and stress management (e.g., common sources and manifestations of stress, stress management techniques to improve mental and physical well-being), guided relaxation exercises (e.g., paced abdominal breathing, abbreviated progressive muscle relaxation, relaxing mental imagery), and a brief instruction in the use of "coping self-statements" [108]. In the SSMT condition, survivors were given a package of instructional resources by a mental health professional during a 10-min session in which a booklet and prerecorded audiotapes that covered the same material and training exercises reviewed in the PSMT were provided [108]. Participation in the SSMT condition was associated with positive effects on quality of life (i.e., better physical functioning, greater vitality, fewer role limitations because of emotional problems, and better mental health) compared to the UC condition [108]. Differences between the SSMT and PSMT conditions were not directly compared, though results indicated that the SSMT intervention led to improvements in quality of life similar to previously reported PSMT intervention effects but at a much more favorable cost [108]. This type of intervention is a promising alternative for survivors with reduced access to psychosocial interventions due to disease- or treatment-related disability or other limitations (e.g., lack of transportation or childcare, insurance coverage). The efficacy and cost advantages of patient self-administered interventions warrant further investigation of techniques that require limited professional time or experience to deliver.

Group Interventions

Group interventions may provide a distinct advantage over individual interventions in several key domains. First, groups provide a setting where survivors may express their feelings to others who share similar experiences, which serve to normalize these feelings and may reduce distress merely through the normalization process and feeling understood by others [20]. Intervention participants can find others who are going through the same or similar experiences with regard to specific treatment regiments and side effects, disruptions to daily routines and functional limitations, and feelings of uncertainty. Participating in a group may buffer the social isolation that frequently occurs after a cancer diagnosis and provide valuable support during difficult times. Social support is needed for successful coping, and group interventions may provide a new and very important social connection and sense of community.

Moreover, many survivors take great pleasure in providing support to fellow group members. This has been termed the "helper-therapy principle" and suggests that many survivors gain new self-esteem by being in a position to share their experiences in ways that will help others undergoing similar difficulties (e.g., "giving back") [20]. For example, one survivor may be able to not only commiserate with fellow members over challenges but may also be able to share tips or novel ways of coping. Members benefit from the rich knowledge gained from the collective experience of the group, sometimes involving information unknown to providers or interventionists, such as creative ways of dealing with a side effect. As such, group interventions provide an opportunity for members to learn from others' experiences while also gaining a sense of accomplishment and self-esteem by helping others in similar and reciprocal ways.

Group composition appears to be an important determinant of intervention efficacy. Differential effects of interventions that include homogeneous (e.g., all distressed) versus heterogeneous (e.g., both distressed and non-distressed) participants have been evaluated, but recommendations regarding the optimal conditions under which to conduct group interventions are inconclusive. Based on theories of social comparison, some studies have shown a greater benefit for participants who report high psychosocial distress at baseline and little or no benefit for those who report low distress (i.e., distressed patients benefit from the presence of non-distressed patients) [109]. The effects of social comparison depend on many different factors (e.g., need for comparison, direction of the comparison [upward or downward], whether the individual identifies or contrasts with the comparison individual, the degree to which the individual feels change with regard to the comparison is possible) [109, 110]. Research-based group interventions are typically homogenous with regard to cancer type and often distinguish between early- and advanced-stage diseases. Further research is needed to determine moderators of intervention efficacy (e.g., disease severity, baseline distress) to better inform theory and clinical practice.

Interventions for Couples and Families

Undoubtedly, the impact of cancer is not limited to the individual patient. Instead, the entire family is often affected. Each family member will have an emotional response and must also adjust to changes in roles and responsibilities and overall family functioning and well-being. Partners, in particular, must cope with worries and fears about the potential loss of their partner and their ability to provide emotional and practical support. Family members routinely provide personal care and help with logistical needs, such as driving to and from appointments, and may be the primary source of support for the cancer survivor. Taking on these responsibilities may be stressful and distressing for caregivers and affected family members. Financial concerns related to medical bills, changes in employment or income, and insurance status may also arise, adding to the stress and burden of cancer. Although spouses/partners and family members are often negatively affected, they typically fail to receive the respite and support they need and access to therapy may be limited.

All phases of the cancer experience have challenges that can be distressing to survivors and partners individually and taxing to the relationship as a whole. Through active treatment and posttreatment transition to survivorship, partners may take a more direct caretaker role. After the end of treatment, as survivors regain their strength and resume precancer activities and responsibilities, couples must navigate the transition in roles and relationship functioning again. Common stressors include changes in role functions, communication difficulties, and sexual dysfunction [71, 73, 75, 111]. Relationship distress may continue even after individual distress is alleviated [71]. Importantly, the effects of cancer may also be positive, such as increased intimacy and marital satisfaction [112]. Nevertheless, despite some indication of overall benefit, many couples will experience some difficulty adjusting to cancer-related changes in their relationship, particularly those who face more advanced-stage disease, more significant side effects or physical dysfunction, greater disruption to daily living, or worse prognostic factors.

Couple-based psychosocial interventions are effective for improving partners' individual psychological well-being and relationship functioning. Specifically, interventions have shown positive effects on communication and marital functioning, distress, appraisal of illness, appraisal of caregiving, feelings of uncertainty and hopelessness, and general and disease-specific quality of life [71, 113–117]. Partners are most often included in dyadic interventions in one of two ways: as a support to the patient learning intervention content and coping skills or by actively intervening on the couple as a unit [117]. Several theories have been identified to explain how couples cope with cancer, including relationship-focused coping, transactional model of stress, and systemic transactional model of dyadic coping [118]. Additionally, self-regulatory theory has been used to explore couples coping with risk or diagnosis of cancer. This theory posits that an individual is likely to respond to health-related threats based on how the individual affectively and cognitively processes threat-related information, so within a couple, each individual will respond and create a complex overall couple response to such information [119]. The majority of couple-based interventions have included heterosexual couples coping with breast and prostate cancers, and interpretations may not generalize to other cancers or couple types. Localized prostate cancer, for example, has a high survival rate, and couples are more likely to focus on treatment-related side effects and long-term adjustment issues, whereas couples coping with lung or pancreatic cancer will most likely have to face end-of-life concerns and open communication about grief and loss. Couples' concerns and demands on the relationship will differ depending on cancer site and stage. Individual and relationship moderators of psychosocial interventions are discussed in more detail below, though gender has been found to play a role in couple responses to the cancer experience with women often experiencing greater levels of distress than men regardless of role (e.g., patient or partner of patient [120].

Caregiver Interventions

It is well recognized that informal family caregivers face their own stresses and psychological burden associated with the physical and emotional toll that comes with providing care to a patient with cancer. Family caregivers may include partners, adult children, or other loved ones that are able to provide support and care. These individuals typically receive little preparation, training, or support to learn and perform their caregiving role. Often in a very short amount of time, they must navigate role transitions with the patient, along with the added responsibilities of managing patient needs, while coping with uncertainty, fears, and other difficult emotions that arise when a partner or loved one faces a cancer diagnosis. "Caregiver burden" is conceptualized as a multidimensional biopsychosocial reaction that results when care demands exceed caregivers' personal, physical, emotional, social, and financial resources given the other multiple roles they fulfill [121]. In most instances, a cancer diagnosis occurs unexpectedly, and both patients and their loved ones are unprepared for the challenges ahead. Those that take on caregiving roles often feel overwhelmed by the added responsibilities, life changes, and emotional difficulties and struggle to continue self-care behaviors. Caregivers have been shown to report high levels of distress, and caregiver burden is associated with increased anxiety and depression over time [122, 123]. Caregiver burden is also associated with physical health complications including sleep difficulties and fatigue, lowered immune functioning, poor health-related behaviors, and greater morbidity [124, 125]. Conversely, there is some evidence for the potential rewards of providing care, including gaining meaning in life and increased appreciation of others [126, 127]. Nevertheless, the psychological and physical symptoms associated with caring for a patient with cancer place caregivers at greater vulnerability for experiencing negative outcomes.

Given these risks, caregiver-focused distress screening is warranted and has been shown to be feasible and perceived favorably by caregivers [128]. A number of systematic reviews of psychosocial interventions for informal caregivers have been conducted [129–135]. Common components of caregiver interventions include psychoeducation, skills training, and therapeutic counseling, commonly based in a cognitive behavioral theoretical framework. Strategies used in cognitive behavioral interventions include cognitive restructuring, coping skills training, problem-solving techniques, behavioral activation, the use of structured homework, and relaxation techniques for stress and anxiety management [134, 136]. Interventions may be delivered to caregivers alone or jointly to patients and caregivers. Psychosocial interventions targeting caregivers have been shown to significantly reduce perceived burden of providing care to the patient with cancer, improved coping ability, increased self-efficacy, improved physical well-being, and improved quality of life. Notably, some evidence suggests the magnitude of effects may only be small to medium, and robustness of findings limited [135], which may depend on baseline caregiver needs and levels of distress, intervention fidelity, and therapeutic approach. Most intervention studies have been conducted with primarily female caregivers, and further work is needed to successfully implement interventions into practice. Widespread programs do exist, representing varied ways of addressing caregivers' needs across settings e.g., [137].

Modes of Delivery

An important consideration regarding the delivery of psychosocial interventions to cancer populations concerns their availability and accessibility. There are barriers that sometimes prevent cancer survivors from attending in-person intervention sessions such as debilitating side effects, geographic distance, and access to transportation, as well as work- and family-related responsibilities (e.g., need for childcare) [108, 138–142]. Additionally, many survivors may prefer not to return to the hospital, which may be a trigger for cancer-related distress [143]. Telehealth and telemedicine options have certainly become more commonplace in recent years, and many survivors may prefer interventions that are delivered remotely via digital health platforms. Home-based interventions that utilize digital platforms or rely on mailed materials may offer greater hope of reaching those that would otherwise be unable or unlikely to participate.

There are several advantages to remote/home-based verse in-person interventions. The modality of delivery is relatively flexible. For example, psychoeducational material may be delivered synchronously (e.g., real-time telephone calls or chat rooms) or asynchronously (e.g., materials that are mailed or emailed). There is also a greater variety of facilitation options including increased scheduling convenience, which may translate to increased access for individuals who would otherwise be unable or unlikely to attend. Depending on the use of technology, remote interventions may require fewer resources and costs than in-person interventions [140, 141].

Digital platforms include the internet, smartphone application (apps), and telephone or telehealth options (e.g., video conferencing). Evidence supports the efficacy of digital interventions across a range of outcome variables. Internet-based psychoeducational interventions have shown significant benefits for survivors of cancer, including decreased depression and fatigue and increased health-related quality of life and cognitive function [144, 145]. For example, breast cancer survivors have demonstrated significant improvements in depression, cancer-related trauma, and perceived stress following a web-based psychoeducational support group (12-week intervention) [142], as well as significant improvements in exercise behaviors and weight gain following a telephone-based physical activity intervention even during adjuvant treatment phases that included chemotherapy and/or radiation [146].

App-based interventions may assist in targeting and engaging populations previously underrepresented in hospital-based psycho-oncology research. Apps may be refined for specific, targeted outcomes, like psychosocial (e.g., fear of recurrence) or physical symptoms (e.g., fatigue), adherence to treatment, and promotion of health behaviors (e.g., exercise and weight loss) [147–150]. Findings suggest that technology-based interventions may be effective in improving disease-specific and general quality-of-life outcomes among patients undergoing active treatment and into survivorship. Technology may be used in combination with more traditional types of interventions to optimize delivery and access, such as using an app, website, or telephone, to compliment and expand in-person intervention support. Additional research is needed to assess the role of ever-changing technology in the delivery and use of psychosocial interventions in cancer populations.

There are some disadvantages and limitations to consider with remote interventions utilizing digital platforms or technology. The most obvious is that individuals must have access to and knowledge of the technology that is required to participate in the intervention including devices (e.g., smartphone, computer) and Internet/Wi-Fi access, as needed. This is particularly relevant to older and rural populations who may not be as familiar with or comfortable using more advanced technology (e.g., “web cams”) or have reliable Internet access. Technological mishaps may be frustrating for intervention participants and disruptive to group processes and cohesion. Intervention facilitators should be aware of potential difficulties and prepared to adjust to whatever problems may arise during the course of the session. The use of mobile phones and internet to deliver an intervention may add additional concerns regarding confidentiality and privacy. For example, group-based interventions via video conference calls carry the inherent risk that non-group members may overhear group discussions or see participants’ faces, or group members may allow non-group members to view postings by participants or see photographs of other members. Participants should be reminded of the limitations of confidentiality and that their postings should be treated as potentially public documents. Despite these limitations and given the barriers to dissemination of in-person interventions, there is a distinct need for remote and home-based interventions. Preliminary evidence indicates that home-based interventions are feasible, affordable, and acceptable to survivors and may be beneficial across disease-specific and general quality-of-life outcomes. Remote technology interventions provide an efficient means of reaching survivors who may otherwise be physically and/or socially isolated or lack the self-efficacy to report problems and seek support.

Interventions Across the Cancer Continuum

Pretreatment Interventions

The number of interventions that have targeted survivors in the pretreatment phase of their cancer experience is limited. Psychosocial interventions have been used to prepare survivors for the likely sequelae of physical and functional side effects and emotional reactions following treatment, and evidence suggests they may be effective in preserving quality of life over the course of treatment. A review of pretreatment interventions suggests that several different types (e.g., psychoeducation, behavioral, coping skills training, relaxation, and guided imagery) administered prior to the start of chemotherapy demonstrated positive effects on treatment side effects (e.g., nausea, vomiting), emotional distress and depression, functional limitations due to disease and/or treatment, and better overall quality of life [108].

Psychoeducation interventions may be used to reduce fear and uncertainty. Reviews suggest that psychoeducation that focuses on what to expect posttreatment and ways to cope with disease- and treatment-related stressors are beneficial. For example, a 90-min “coping preparation” intervention for survivors about to start chemotherapy included a tour of the oncology clinic, provision of videotaped and written materials about coping with the effects of treatment, and a discussion session with a therapist and was combined with a relaxation training intervention. Compared to relaxation training alone and a standard treatment control condition, the combined coping preparation plus relaxation training intervention resulted in less anticipatory nausea, less depression, and less interference in daily life from disease- and treatment-related effects [29, 151]. Similarly, a psychoeducation intervention consisting of only a brief (15–20 min) meeting with a counselor delivered at the time of the initial treatment consultation with the medical oncologist and designed to orient the survivors with the facility and prepare them for their treatment (i.e., included a tour of the oncology clinic and treatment procedure rooms, description of clinic procedures, provision of contact information for clinic services and local and national support services, and a question and answer session) demonstrated positive effects on anxiety and depressive symptoms and satisfaction with medical care compared to usual care alone [151].

Interventions administered prior to the start of treatment that attempt to prepare survivors to cope with treatment-related challenges and side effects may have a beneficial impact on physical and psychosocial outcomes. Behavioral interventions that consist of relaxation training (e.g., progressive muscle relaxation and guided imagery techniques) prior to the start of chemotherapy resulted in fewer treatment-related side effects (e.g., nausea, vomiting), less psychological distress, and better overall quality of life compared to standard treatment control conditions [29, 152]. Likewise, relaxation and stress management interventions administered prior to surgery significantly improved postoperative mood and quality of life, and some evidence suggests that benefits may extend beyond the perioperative period. For example, a preoperative interview with either a 30-min psychotherapeutic intervention or chat with a consultant surgeon trained in listening and counseling skills was effective in improving adaptive coping strategies and reducing body image distress, depression, and anxiety compared to standard care alone among breast cancer survivors at 3 months post-surgery (some effects continued up to 12 months post-surgery) [153]. The psychotherapeutic intervention was superior to the chat with a surgeon condition only among participants who reported severe stressful life events, highlighting the increased need for distress screening and targeted intervention for at-risk survivors [153].

Findings support the utility of cognitive behavioral and relaxation techniques, specifically, to enhance stress management and adaptive coping skills and suggest that interventions do not necessarily have to be extensive in nature (i.e., one to two sessions). Further research is needed to determine the specific timing of optimal intervention design (e.g., time-limited prior to treatment versus ongoing throughout treatment course) and to identify those survivors most likely to benefit from different treatment components (e.g., relaxation training versus cognitive stress management techniques). Although pretreatment interventions among cancer survivors are limited, interventions conducted prior to treatment in other disease populations further support their utility. For example, the provision of stress management and relaxation techniques prior to surgery in various non-cancer patient populations has been associated with less pain and use of analgesic medication, lowered blood pressure, less distress, and better quality of life in following surgery [154].

Interventions Conducted During and Immediately Following Treatment

The vast majority of psychosocial interventions in cancer survivors have been conducted either during active treatment or in the first year following the termination of primary treatment. Reviews of the literature have suggested positive effects on a range of outcomes, including psychosocial and behavioral well-being, and general and disease-specific quality of life [155]. These are reviewed below.

Emotional and Physical Well-Being and Quality of Life

Reviews of the literature support the efficacy of psychosocial interventions among cancer survivors during and immediately following active treatment, particularly regarding their effects on emotional well-being. Emotional well-being outcomes have included distress, anxiety and depression, anger, self-esteem, optimism, and self-efficacy. Interventions promote better understanding of illness, self-efficacy, having a more positive outlook, benefit finding, and hope for the future. Important physical outcomes include pain, sleep disruption or insomnia, vigor, and fatigue. Group-based cognitive behavioral interventions appear to be efficacious in improving emotional well-being and quality of life in cancer survivors in the posttreatment period, while improvements in physical functioning may be less prominent [30]. Cognitive behavioral interventions, specifically, have been related to short-term effects on anxiety and depression and both short- and long-term effects on depression and quality of life [29]. Group interventions that utilize cognitive behavioral approaches have considerable potential to be incorporated as a routine part of clinical care offered to survivors finishing treatment to promote positive adjustment to cancer survivorship, and remote delivery should be considered to increase accessibility and convenience for participants. Similarly, stress management and relaxation training are effective and feasible intervention components to improve coping, emotional well-being, and quality of life among survivors undergoing active treatment and in the transition to posttreatment survivorship. The majority of psychosocial interventions for cancer survivors focus on dimensions of psychological distress and health-related quality of life; greater attention should be paid to mechanisms of action (i.e., psychological and physiological processes that promote positive outcomes) [156]. Although cognitive behavioral and stress management approaches are suggested as viable and effective interventions, further research is needed to improve long-term benefit.

Immune Function

Psychoneuroimmunology is an area of growing interest that focuses on the complex interplay of illness, immunity, and psychosocial factors. Stress is one factor that has been identified as playing a key role in the development, progression, and fight against cancer [157]. Immune function is a primary pathway through which the impact of stress and other negative psychosocial factors impact patient health and well-being. A variety of physiological and biological markers may be measured to assess immune function, such as levels of immune cells (e.g., lymphocytes, natural killer cells, T-cell activity), inflammatory factors (e.g., cortisol, interleukin (IL)-2, IL-6, IL-10, C-reactive protein, cytokines), and expression of disease and metastasis-related genes or receptors [157, 158]. Negative psychosocial factors, such as chronic stress, distress, depression, poor social support, disrupted sleep, and perceived social isolation, have been associated with negative changes in the immunity of patients with cancer, such as dysregulated cortisol slopes, increased inflammation, decreased white blood cell counts, and damaging oxidative cellular stress [157, 159–161]. Furthermore, negative PNI changes, like these, have been linked with worsened patient morbidity, mortality, and disease prognosis.

Behavioral and psychosocial interventions intend to alter such emotional and psychosocial states, in turn facilitating changes in immune function, and ultimately improving clinical outcomes. Psychosocial interventions include individual therapies (e.g., expressive writing, cognitive-behavioral therapy, massage, relaxation and visualization training, psychoeducation, hypnosis) and group programs (e.g., cognitive behavioral stress management, mindfulness-based stress reduction, Qigong, yoga, body-mind-spirit) [162]. Recent reports suggest interventions based in cognitive behavioral therapy are most effective in improving immune outcomes [163], which may be mediated by components of mindfulness that act on downregulating sympathetic nervous system activation caused by stress [164]. Patients who received group interventions have improved short-term (e.g., 1 year) survival, compared to individual interventions or controls. However, results are mixed, often report small effect sizes, and vary by stage and disease type, thus warranting further research in this area [158, 165–168]. PNI pathways in the body show promise and warrant further attention as outcomes in psychosocial interventions due to their involvement in important clinical indicators, like survival.

Survival

Very few psychosocial or behavioral intervention studies conducted in cancer have examined survival as an outcome, and conclusions regarding improvement in survival time following participation in an intervention are preliminary. Although some studies have reported beneficial effects on survival time (e.g., supportive-expressive group therapy [169–172], psychosocial behavioral intervention [173, 174], psychoeducational intervention [175], intervention to improve medication compliance [176]), other studies have found no significant survival benefit of participation involving various forms of psychotherapeutic intervention [171, 177, 178]. Efficacious studies have been conducted in several cancer populations, including breast and malignant melanoma, with follow-up times of up to 10 years post-intervention [87]. Common factors among those interventions that demonstrated significant effects on survival have been identified [179] and include (1) group compositions that were homogenous with respect to cancer type and stage and (2) interventions that included an educational component, stress management, and coping skills training [179]. However, in a meta-analysis of the effect of psychosocial interventions on survival time in cancer, neither randomized or nonrandomized studies indicated a significant effect [179]. The authors highlighted several methodological limitations in making comparisons across studies due to significant variability with respect to cancer types and stage, intervention components, and follow-up times [179].

Several psychosocial factors have been linked to the development and progression of cancer and have been shown to be important considerations in cancer care, including helplessness/hopelessness coping style and social isolation. It is plausible that interventions that alter modifiable risk factors may significantly impact prognosis and survival. For example, high levels of perceived stress have been shown to have suppressive effects on immune function, and this relationship may be modulate by social support [180]. Psychosocial interventions that aim to reduce perceptions of stress, improve physical and emotional well-being, and achieve optimal immune function may very well influence relevant disease-related factors related to prognosis and survival. Conclusions regarding the benefit of psychosocial interventions on survival should be interpreted with caution, but theory and empirical evidence provide rationale for further investigation.

Mixed Findings

While there have been many reviews that have strongly supported the benefit of psychosocial interventions on emotional and physical well-being, adjustment to disease- and treatment-related side effects, and quality of life, others have offered only tentative recommendations or have cited insufficient evidence with which to make recommendations for or against the use of interventions. Meta-analyses have cited several problems in how results are reported in the literature such as low quality of methodology and inconsistent findings regarding intervention efficacy [181–183]. One reason for inconsistent findings is the inclusion of survivors who are not in need of psychosocial support and lack of individualized and targeted intervention strategies. Reviewers have recommended that large-scale studies should screen survivors for distress prior to enrollment [178]. Additionally, few interventions have reported mechanisms of change associated with positive outcomes.

Taken together, evidence suggests that psychosocial interventions need to be employed with greater awareness of moderating factors associated with emotional distress and intervention efficacy as well as mechanisms of change associated with active verse inactive intervention components. To this end, intervention components may be developed with greater specificity to target cancer populations and subpopulations characterized by different sociodemographic and health-related factors and psychosocial needs. A greater understanding of factors that are associated with increased risk of poor adjustment and active therapeutic mechanisms will result in refinements to interventions that enhance efficacy and inform underlying theory.

What Works for Whom?

Sociodemographic Factors

Age Evidence suggests that younger survivors are more likely to experience emotional distress (e.g., depression and anxiety) in response to cancer and its treatment than older survivors, particularly among women [28]. This may be due to younger survivors feeling more unprepared to cope with a serious threat to their health and mortality, particularly if other responsibilities (e.g., parenting of younger children) are a concern. Conversely, older survivors (>65 years) may already be coping with age-related declines in physical health or may have peers that have faced similar (or worse) health challenges and therefore better equipped to negotiate cancer-related changes. For example, despite experiencing significant treatment-related disruptions to physical well-being, localized prostate cancer survivors often report above average levels of emotional well-being compared to age-matched normative populations [184].

Socioeconomic Status Disparities in quality of life among cancer survivors may be explained in part by differences in socioeconomic status (SES). High-income survivors are not only more likely to survive cancer but have greater access to resources and report higher levels of quality of life than low-income survivors [47]. Cancer diagnosis and treatment may exacerbate socioeconomic difficulties, or socioeconomic concerns may arise from cancer treatment such as financial stress related to costs of care, access to health insurance, and the ability to continue or return to work or school. Individuals characterized by lower SES may be in greater need of psychosocial interventions designed to address stress management and active coping skills to access resources and meet global needs of daily living such as dependable access to food and shelter. Some evidence suggests that survivors who report lower SES may benefit more from interventions than those who report higher SES, but this likely depends on the type of intervention and targets of therapy [185].

Ethnicity and Cultural Backgrounds Ethnic minorities are more likely to experience greater difficulty adjusting to cancer and greater decrements in quality of life, as well as worse health outcomes, including more frequent recurrence, shorter disease-free survival, and higher mortality rates [186–188]. Immigration status and language barriers pose additional challenges in accessing care and getting cancer needs met [189]. Despite this, few interventions have been tailored to meet the specific needs of ethnic minorities with different cultural backgrounds, and limited evidence has evaluated the extent to which ethnic and cultural differences are associated with intervention efficacy [91, 190, 102]. Furthermore, strategies to achieve cultural appropriateness within psychosocial interventions for ethnic minorities have largely focused on recruitment and retention efforts and have not focused enough on ensuring that sociocultural concepts are incorporated into content of the intervention [191]. Although some efforts are underway [192, 193], cultural adaptation of evidence-based interventions for ethnic and cultural subgroups is a priority area in psycho-oncology.

Medical Factors

Not surprisingly, more advanced disease is associated with greater likelihood of psychological distress and worse physical functioning and overall quality of life. As such, there is an increased need for effective psychosocial interventions in this patient population. Support-expressive therapies and cognitive behavioral therapy have been shown to be effective in preventing or relieving depression and anxiety among survivors with metastatic disease; relaxation techniques, alone or in combination with education/skills training, may be more effective in preventing or relieving depression and anxiety among survivors in the terminal phase of their disease [46].

Physical and Emotional Well-Being

Cancer survivors who report significant distress and/or disability throughout the cancer continuum are likely to be in need of psychosocial interventions, and limited evidence suggests that intervention efficacy may vary depending on baseline levels of physical and emotional well-being [194]. Furthermore, interventions designed for cancer survivors experiencing heightened levels of psychological distress have demonstrated immediate and sustained intervention effects [22, 29]. Finally, as the stress of cancer often exacerbates prior psychiatric symptoms or mental health disorders, identifying those who may be at increased risk for clinically significant symptoms based on their mental health history may also be important.

Perceived Stress

The degree to which cancer survivors appraise their situation as being unpredictable, uncontrollable, or overwhelming has significant implications for their emotional well-being [172, 195, 196]. Perceived stress has been shown to be a significant moderator of intervention effects on emotional well-being such that those with higher levels of perceived stress at baseline report significantly greater improvements in emotional well-being following participation than those with lower levels of perceived stress at baseline [197]. Similarly, greater severity of lifetime stressful events has been associated with greater benefit from interventions including improvements in adaptive coping skills and emotional well-being (e.g., depression, anxiety, body image distress) [153]. As perceptions of stress and stress management skills have been significantly related to lowered emotional well-being, physical functioning, and lowered quality of life, findings suggest an increased need for screening and targeted interventions for survivors with high levels of perceived stress.

Social Support

Higher levels of social support are associated with better general and disease-specific quality of life, and, conversely, social constraints (e.g., avoidance of cancer-related discussions) are associated with worse emotional well-being and quality of life [198, 199]. Cancer survivors with less social support and fewer interpersonal resources with which to cope are at increased risk for experiencing emotional difficulties and decrements in quality of life and are more likely to benefit from psychosocial interventions. Social isolation, living alone, and being unmarried or unpartnered negatively affect psychosocial outcomes and mortality [200]. Among breast cancer survivors, lack of personal resources (i.e., low self-esteem, low body image, low perceived control, and high illness uncertainty), low partner-specific emotional support, and lack of physician informational support have been shown to be associated with intervention efficacy, independent of socioeconomic status, and disease stage [201]. Similar findings have been reported among male cancer survivors and suggest that single men, compared to single women and married or partnered men and women, may be particularly vulnerable to psychosocial and health-related morbidity due to low levels of support [200, 202]. It remains unclear whether men would also benefit from emotional support interventions despite reluctance to admit as much, and evidence suggests the importance of considering social support as a moderator of intervention effects. Young adult survivors are also at higher risk for support deficits given their unique stage of social development and lower chance of knowing same-aged peers with similar cancer histories and report peer support as a primary unmet need in survivorship.

Coping Styles

Research suggests that different coping styles are differentially related to adjustment and well-being. Generally speaking, greater optimism and active coping styles relate to more positive adjustment [203, 204]. Approach, problem-focused, and emotion-focused coping strategies (e.g., seeking social support) are associated with better physical and emotional well-being, whereas avoidant coping (e.g., disengagement, cognitive avoidance) is associated with worse outcomes [52, 205–207]. Approach coping has been related to better self-esteem, positive affect, and lower depression and anxiety symptoms, whereas avoidant coping relates to worse psychological adjustment and physical functioning [207]. Among a mixed sample of male cancer survivors, avoidant coping was associated with greater severity of sleep disruption and more interference with daily functioning; increased depression was identified as a significant mediator of the relationship between avoidant coping and sleep disruption [208]. Women with gynecologic cancer undergoing extensive chemotherapy who reported greater use of avoidant coping were also more likely to report poorer physical and emotional well-being and greater anxiety, depression, fatigue, and total mood disturbance; those using active coping reported less distress, better social well-being, and closer relationships with their doctors [209]. Evidence also suggests that negative effects associated with avoidant coping may be more pronounced among survivors with advanced-stage disease and/or extensive treatment regimens [210]. Alternatively, emotion-focused coping may be more effective among survivors with advanced cancer than problem-focused coping [206]. Findings are mixed regarding the effects of religious or spiritual coping, though evidence suggest that this type of coping may be particularly relevant in advanced-stage disease and during end-of-life care [43, 44]. It has been postulated that avoidance and denial coping may be beneficial to some individuals, particularly those who may not have adequate intra- or interpersonal resources with which to acknowledge and accept the full extent of disease- and treatment-related challenges [206]. The effectiveness of these coping strategies among subgroups characterized by different psychosocial needs requires further evaluation.

Accessibility of Care

As described in this chapter, there are a wide variety of formats, delivery modalities, and content provided in psychosocial interventions for cancer patients. An additional area of interest includes accessibility of such interventions and care: if we develop effective interventions, how do we get them to those in need? A key step to providing accessible care is to first identify those in need, and we previously discussed the need for distress screening before, during, and after cancer with appropriate follow-up and referral. Additionally, interventions to improve care coordination, including patient navigation, case managers/coordinators, and patient-centered care approaches, are key for assisting patients and loved ones to access appropriate care, resources, and support. Cancer care coordination interventions are generally well-received and have effectiveness across several clinical outcomes, including increased appropriate healthcare utilization in urgent, primary, and end-of-life care settings, decreased costs of healthcare utilization in cancer survivors, improved psychosocial outcomes of patients, and decreased hospitalizations and emergency department visits [211]. Additional studies found encouraging improvements in satisfaction of cancer care after receiving patient navigation; however, few rigorous studies exist to characterize this relationship [212]. Such findings support additional research to investigate and integrate these interventions into cancer care settings.

Nontraditional methodological designs of research trials testing psychosocial oncology interventions, such as multiphase optimization strategy (MOST), sequential multiple assignment randomized trials (SMART), and implementation designs, may lend insights into accessibility of who, when, and how interventions should be provided. MOST designs offer a three-phase approach to identify which components of a multifaceted intervention are most “active” or effective [213, 214]. SMART designs utilize re-randomizing participants to varying lengths of intervention to assess the adaptability or benefits in variation of an intervention [213]. MOST and SMART design trial findings are limited in psychosocial oncology research; however, trials are currently underway to explore these methodologies [214–216]. Both MOST and SMART designs aim to identify potent and effective intervention components that may be later tested in traditional randomized controlled trials (RCTs), thus increasing efficiency of intervention development [213, 214]. Implementation and dissemination research designs are at the forefront of psychosocial oncology as critical steps for increasing access and integration of care. Barriers to implementation and dissemination exist at patient, provider, and healthcare system levels [8]. Recommendations for implementation of interventions include pragmatic design elements of trials, intervening at multiple levels (e.g., patient, caregiver, family members, clinical care providers, organizational settings), and conducting hybrid effectiveness-implementation study designs [217]. Ultimately, accessibility of care encompasses patient (e.g., care coordination and patient navigation), organizational (e.g., screening and identifying those in need), and methodological (e.g., methodological design and systematic implementation) approaches in the development and delivery of psychosocial interventions in the oncology setting.

Stepped Care

There are multiple ways of intervening in cancer survivorship to address psychosocial needs and distress. Regardless of the intervention approach, it is important to consider the distress continuum

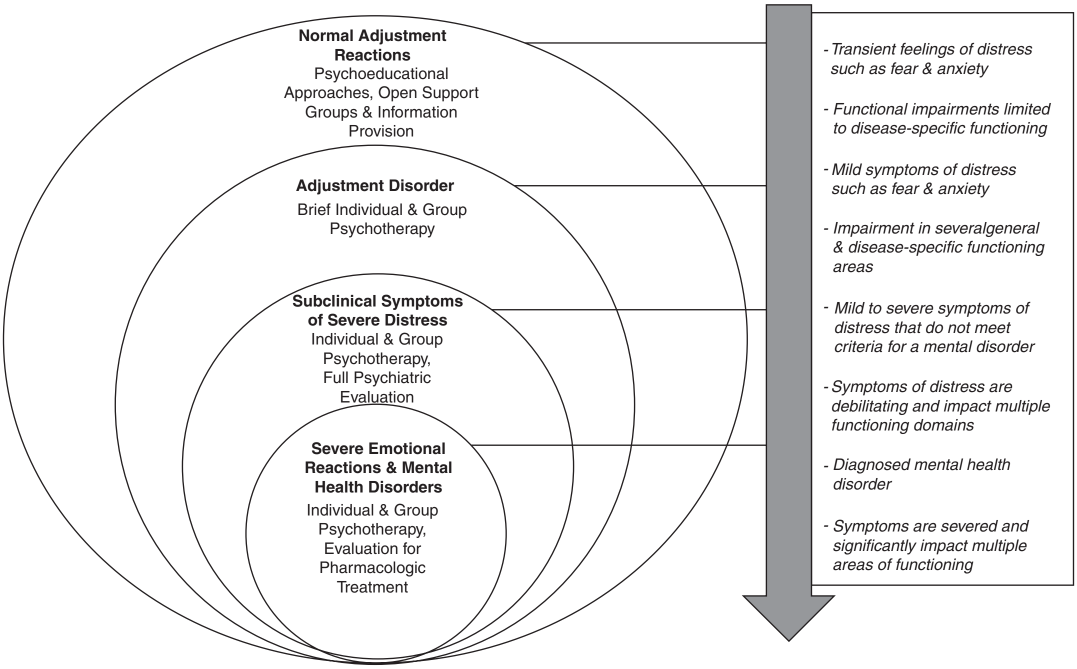

Fig. 10.2 Psychological intervention stepped approaches as a function of emotional reactions across the cancer distress continuum

among cancer survivors to determine the most optimal level of care based on their needs (see Fig. 10.2). Psychosocial intervention is not necessary for all survivors, and a stepped care model of intervention delivery is recommended. This involves a collaborative care approach in which survivors are involved in treatment planning and therapeutic resources are utilized based on systematic assessment and monitoring of survivors' psychosocial well-being. Stepped-care approaches stipulate that treatments of different intensity are provided depending on the need of the individual, thus creating an individualized treatment plan. Treatments are initially implemented that are of minimal intensity but still likely to provide benefit and progress to more intensive interventions only if survivors do not demonstrate improvement from simpler approaches or for those who can be reliably predicted to not likely benefit. An important feature of the stepped-care model is that progress and decisions regarding intervention efforts are systematically monitored and changes in outcomes of interest are carefully assessed. A "step-up" to a more comprehensive therapy is made only when there are not significant gains in the targeted outcomes. Stepped care may involve increasing intensity of a single therapeutic approach, transition to a different therapeutic approach, or using several therapeutic approaches additively. Likewise, different interventions may be applied to address different aspects of a patient's problem. Psychosocial needs also change as survivors move through their cancer experience and either transition to survivorship or face advanced disease and end-of-life concerns. Utilizing a stepped-care approach to promote adjustment and well-being at all phases of the cancer experience may enhance intervention efficacy through more stringent assessment methods and appropriateness of intervention techniques, while also conserving therapeutic resources.

The model in Fig. 10.2 proposes that treatment planning and intervention efforts must consider the distress continuum among cancer survivors to determine the most optimal level of care as the majority of individuals experience some transient levels of distress at diagnosis. For most, emotional reactions will be transient and significantly below clinical levels, and effective interventions include information provision or psychoeducational approaches that offer information on what to expect from treatment, the recovery process, available options for coping with side effects, and skills to effectively navigate the healthcare system or to communicate with loved ones. A minority but yet significant number of survivors may experience emotional reactions that warrant a more structured approach to psychological care. In such cases, brief individual and group psychotherapeutic approaches can be useful in ameliorating persistent symptoms of distress. Cancer survivors who experience subclinical manifestations of mental health disorders such as anxiety, depression, and PTSD (i.e., experience severe symptomatology but not meeting diagnostic criteria) may benefit from a full psychiatric evaluation to determine the most appropriate level of care. For these survivors, individual and group psychotherapeutic approaches can positively impact mental health and health-related quality-of-life outcomes. Among the subgroup of survivors who experience severe emotional reactions and are diagnosed with a mental health disorder, evaluation for pharmacologic treatment, in addition to individual and group psychotherapeutic approaches, is warranted.

Summary and Future Directions

Several psychosocial intervention models in cancer have shown success in reducing distress, improving quality of life, and facilitating the overall posttreatment adjustment period. Psychosocial treatment approaches have ranged from open support groups and psychoeducational programs that are based on information provision to supportive group therapy approaches and individual treatments that are structured to provide a nurturing environment to express concerns over the multiple challenges associated with cancer survivorship. Both individual- and group-based interventions based on cognitive behavioral intervention models that blend a variety of therapeutic techniques (e.g., cognitive restructuring, relaxation training) have shown success in improving health-related quality of life across multiple cancer populations. Other intervention approaches include mindfulness-based stress reduction, emotional expression, symptom management, health behavior change, and motivational interviewing. A significant amount of research has shown that effective therapy components in multimodal intervention efforts include techniques such as relaxation training (e.g., guided imagery) to lower arousal, disease information, and management, an emotionally supportive environment where participants can address fears and anxieties, behavioral and cognitive coping strategies, and social support skills training. Therapeutic processes by which participants benefit from intervention include giving and receiving information, sharing experiences, reducing social isolation, and providing survivors with coping skills that facilitate self-efficacy and sense of control over the cancer experience. Some evidence suggests that cancer survivors may benefit more from structured interventions than purely supportive ones; this may be due to learning skills with which they can more effectively cope with cancer-related changes after the intervention has ended (e.g., stress management). Interventions may also be couple- or family-based, depending on the goals of therapy and targeted outcomes, and may be administered at all phases of the cancer continuum, from post-diagnosis and treatment decision-making to end-of-life or long-term survivorship time periods. Such interventions can be delivered via several modalities including face-to-face and technology-based individual and group-based formats.

There is a large literature documenting the effectiveness of psychosocial intervention with cancer survivors. Interventions have demonstrated positive effects across a range of psychosocial and physical outcomes, including symptoms of depression and anxiety, and cancer-related fear, social functioning, and disease- and treatment-related symptoms (e.g., fatigue, nausea, pain). Although findings have been mixed with reports of nonsignificant effects as well, several reviews of the literature have concluded that the majority of psychotherapeutic interventions among cancer survivors demonstrate some improvement in psychosocial adjustment. Notably, sociodemographic factors (e.g., age, education, and socioeconomic status), premorbid psychological and physical functioning, social support, coping styles, and certain personality traits (e.g., neuroticism, interpersonal sensitivity, and social inhibition) have been associated with increased risk of adjustment difficulties following cancer diagnosis and treatment, suggesting that there may also be considerable variability in baseline functioning and response to intervention efforts.

There are also notable gaps in the literature regarding benefits of psychosocial interventions for survivors with certain demographic, disease, and treatment characteristics. This is particularly true for ethnic and racial minorities, and there is a critical gap in our understanding of whether interventions need to be specifically tailored for ethnic and racial minority groups. A significant amount of the work has also focused on more common cancers, and less is known regarding the utility of conducting psychosocial interventions among cancer survivors diagnosed with less common cancers, which are typically associated with greater treatment-related compromises, greater distress, and poorer survival rates.

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