

National Cancer Survivorship Resource Center

Quality of Life: Programs and Navigation

Expert Panel Summit Workgroup Overview

National Cancer Survivorship Resource Center

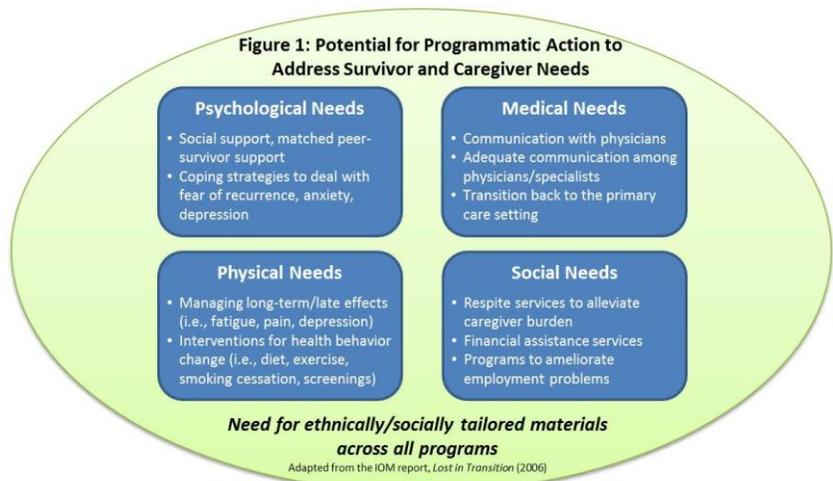
Quality of Life: Programs and Navigation Overview

Survivorship Programs: Support Beyond Treatment

As discussed in the Institutes of Medicine (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2006), the transition out of active treatment creates new complexities for cancer survivors and caregivers. For example, survivors are faced with uncertainties over whom to contact about symptoms; survivors also face difficulties when trying to navigate the healthcare system and deciding who should provide ongoing survivorship care (Oncologist, Primary Care Provider, or both). Furthermore, guidance for survivors transitioning from acute treatment to post-treatment remains limited. Studies show (Chung et al., 2009; Hamilton et al., 2010) that the quality of cancer care provided to individual survivors varies greatly; the poor as well as racial, linguistic and cultural minorities often receive the most disconnected, untimely and ill-managed care, with health outcomes substantially worse than those experienced by more affluent, white counterparts (ACS, 2010).

Cancer and its treatment is often referred to as a “teachable moment” (Ganz, 2005), wherein the illness experience provokes readiness for behavior change and sustainable lifestyle benefits. It is within this moment that health behavior interventions can develop the most traction and have the greatest potential for long-term success through the cancer continuum and into survivorship. In addition, psychosocial interventions have been shown to benefit survivors, especially those with high levels of distress (Redd et al., 2001). Psychosocial support programs vary based on characteristics of the population: age, race/ethnicity, socioeconomic status and geographic location, etc. Areas of potential for programmatic action are listed in Figure 1.

There are numerous survivor (McDowell et al., 2010; Mikkelsen et al., 2009; Schlairet et al., 2010) and caregiver (Campbell et al., 2009; Golant & Haskins, 2008; Kim et al., 2010) concerns, such as anxiety (Elsesser et al., 1994), depression (Simpson et al., 2001), fear of recurrence (Humphris & Ozakinci, 2008), pain (Yates et al., 2004), fatigue (Bower et al., 2006) and sexual dysfunction (Brotto, 2008). While evidence-based interventions do exist and can be effective if implemented appropriately, many symptoms often go undiagnosed and are poorly managed. In addition, those survivors and caregivers who are uneducated, poor, uninsured, under-insured or who face language barriers are disproportionately affected. Therefore, ethnically/socially tailored interventions, including the provision of patient navigation and other support services during the post-treatment transition phase, have the potential to dramatically improve quality of life (Harrington et al., 2010).



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Barriers to effective post-treatment survivorship care have been synthesized from the literature review and thematically summarized below:

- **Survivorship Care is Not Defined:** Without a clear and accepted definition of a cancer survivorship program, there is ambiguity about what services the program should include or who the program should serve.
- **No Consensus on Evaluation Measures:** Due to the growing number of survivors, efforts are being made to assess survivors' needs and develop programs to meet these needs. However without consensus-based indicators to measure the success of these programs, there will be little ability to demonstrate effectiveness and measure program impact on improving survivor quality of life (Hewitt et al., 2006). Although there are several scales that measure quality of life and psychosocial symptoms (e.g., Cancer Rehabilitation Evaluation System- Short Form, Functional Living Index-Cancer, Impact of Cancer Scale), a gold standard has not been identified to measure psychosocial functioning and needs in survivors.
- **Diverse Survivor Populations:** Cancer survivors have many different needs, which can vary based on age, race/ethnicity, socioeconomic status and geographic location. Thus, programs addressing survivors' issues related to the transition into recovery should not be delivered through a one-size-fits-all approach.
- **Lack of Health Care Professional Education:** In order to successfully facilitate survivorship programs and interventions, health care professionals need to be trained on how to accurately assess the needs of survivors and how to administer programs or appropriately refer survivors to other resources.

Following is the Quality of Life Programs and Navigation workgroup's evaluation of current post-treatment survivorship programs and navigation services and recommendations for future directions.

Workgroup Progress: Identifying Gaps and Developing Strategies

The workgroup focused on the psychosocial needs of cancer survivors and how survivor programs and survivorship navigation can be used to help meet those needs. The workgroup discussions had two major themes: 1) Defining a survivor program, what it consists of, how it can be evaluated and who it will reach; and 2) The importance of provider education, awareness and support of cancer survivors' psychosocial needs and appropriate resource referral. Clinical survivorship care was addressed separately by the Clinical Survivorship Care Workgroup.

Program Definition, Evaluation, and Reach

Although the terms *cancer survivor* and *survivorship* have been defined by various organizations, the workgroup recommended that a definition of a *cancer survivorship program* be developed in order to establish a standard for survivorship care. Multiple iterations of the definition of a cancer survivorship program were developed before settling on this consensus-based definition: *The goal of a cancer survivorship program is to maximize the quality of life of survivors and their caregivers. The program should include a comprehensive set of services provided by multidisciplinary groups working together to assure effective medical care, education and emotional support. Communication between and among*



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survivors, their caregivers and providers is essential for the seamless referral, navigation and coordination of these services.

Workgroup members were asked to provide information about support programs for post-treatment survivors, which included whether the programs were evaluated and if the programs were ethnically/socially tailored to specific populations. This exercise confirmed two gaps: 1) survivorship programs lack consensus-based performance measures to demonstrate program success and elucidate areas of improvement; and 2) there is limited information on the availability of resources for post-treatment survivors and this gap is even larger for those who are ethnically and socially diverse.

To address the lack of evaluation measures, the workgroup identified various core outcomes and measurement tools that could be applied across survivorship programs. Based on this information, a Program Evaluation Guide was created to assist survivorship programs with program evaluation and to encourage consistency of evaluation processes across programs. Evidence-based programs should become more common-place as more survivorship programs approach program evaluation with consistent methods and measures. To address the second gap, the workgroup was surveyed for effective methods used for reaching ethnically and socially underserved populations. This activity revealed a stark paucity of resources for ethnically/socially diverse survivors. To further inform this work, the National Cancer Survivorship Resource Center will conduct an assessment of evidence-based programs available through cancer centers nationwide to develop a Cancer Survivor Resource Inventory. This inventory will be used to inform a publically available repository of cancer survivorship resources and programs. Workgroup members agreed that more survivorship programs and navigation services must consider the specific needs of the ethnically and socially underserved communities and collaborations among community partners and national organizations are critical in order to identify and effectively meet the needs of these groups.

Health Care Professional Awareness and Education

The second theme of discussion focused on the lack of health care professional awareness and education on post-treatment survivorship issues (psychosocial and physical), supportive care needs and how these issues affect the provision of survivorship care. Workgroup members agreed that there is a large gap between health care professionals' education and the demands of survivorship care on the health care system. With a fragmented health care delivery system, there is insufficient cross-communication among health care professionals of different specialties and program coordinators/administrators, which inhibits the ability to deliver care that is both timely and effective. The workgroup recommended various strategies to educate health care professionals, increase health care professionals' awareness about survivorship programs and improve the overall delivery of survivorship care. Recommendations include: CME-eligible training courses delivered online or in-person, a multidisciplinary survivorship care curriculum for undergraduate and graduate medical education (including nurses and social workers), guidance on utilization of a survivorship care plan and a comprehensive database of survivorship resources that can be easily accessed by health care professionals as a mechanism for service referral.



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Recommendations for the Future

The workgroup developed a recommendations matrix that included recommendations, performance indicators and identified gaps. The matrix is structured using the socio-ecologic framework, focusing on individual/survivor, organization/health care system and society/policy levels of intervention in the four essential areas of survivorship care: healthy habits, early detection disease surveillance, psychosocial and physical post-treatment side effects and provider communication. These recommendations are described in the following section.

Survivors

Recommendations that directly impact survivors primarily focus on program reach, needs assessment measures and health care professional communication tools. Although evidence-based programs to promote nutrition, physical activity, disease surveillance and effective coping techniques exist, they should be tailored to meet the specific needs of ethnically and socially diverse survivors. To ensure consistent and appropriate program referral, a core battery of needs assessment measures should be identified. The workgroup agrees that survivors need information about how to effectively communicate with health care professionals, particularly with regard to unmet needs.

Health Care System

Recommendations for the health care system are primarily centered around cultural competency among health care professionals and staff working in survivorship clinics, the inclusion of survivorship navigators and the need for publically-available survivorship program information. The workgroup recommends that program directors examine their staff composition to ensure that staff reflect the diverse communities being served. The workgroup also recommends the inclusion of a survivorship navigator as part of the multidisciplinary health care team to assess survivors' support service needs, ensure a survivorship care plan/treatment summary is created and educate the survivor on the importance of identifying and maintaining a medical home. If financial limitations prevent the inclusion of a dedicated survivorship navigator as part of the health care team, existing health care professionals' knowledge and skills should be enhanced to optimize survivor resource acquisition and empowerment as survivors transition to the post-acute care period. Lastly, the workgroup recommends the development of an easily accessible system for health care professionals, survivors and caregivers to go to for educational materials and supportive care resources aimed at the post-treatment phase of survivorship.

Society/Policy

While the workgroup mainly focused on the development of strategic recommendations specifically for survivors and the health care system, there was consensus around the need for policy advocacy to ensure the use of treatment summaries and survivorship care plans.

Indicators to Measure Progress

Without evidence of the effectiveness of services and programs, cancer survivors cannot easily make personal health decisions, health care professionals lack the clinical practice guidelines necessary to optimize care and insurers and payers lack the guidance needed to ensure that appropriate care is accessible and affordable (Hewitt et al., 2006). Performance indicators were developed based on the workgroup discussions and strategic recommendations. Additional work is needed to determine the specific measures, establish baseline value and set specific outcome goals for each of the performance



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indicators. An assessment of the current capacity of nationwide surveillance systems to support the measurement of these indicators is underway; once capacity is determined, recommendations for measures or proxy measures corresponding to each performance indicator will be developed.

Table 1: QoL: Programs and Navigation Performance Indicators

Outcome Domain	Outcome Goal
Healthy Habits	Increase in the number of survivors counseled about healthy habits
	Increase in self-reported positive (healthy) behavior change
	Increase in the proportion of survivors that maintain healthy weight
	Decrease in the number of (or improved management of) co-morbid conditions
Early Detection / Disease Surveillance	Increase in the number of survivors who follow-up on recommended referrals
	Increase in the number of survivors who are compliant with referrals
	Increased adherence to recommended screening guidelines
	Increase in screening rates
Post-Treatment Side Effects (Psychosocial and Physical)	Reduction in the number of long-term and late effects reported by a standardized tool (e.g., PHQ-9; Pain Scale; Distress Thermometer; etc.)
	Positive change in the patient satisfaction of survivorship care and mitigation of long-term effects
	Increase in the number of survivors enrolled in a psychosocial support program
	Increase in the number of survivors participating in an educational program on how to manage long-term and late effects
	Higher level of program satisfaction
	Improvement in tracking the number of referrals to other providers/programs
	Increase in the number of survivors referred to other providers/programs
	Increase in number of survivorship care plans/treatment summaries, including educational materials regarding survivorship issues, given to survivors and their primary care providers
Health Care Professional Communication	Increase in awareness of quality of life issues among post-treatment survivors
	Increase in use of evidence-based survivor-provider communication tools
	Increase of support for survivorship programs and services
	Development of a communication mechanism for “major players” in the survivorship care arena
	Identify and adopt common performance indicators/measures of success across survivorship programs
	Increase in recognition of survivorship navigation as an integral part of a multidisciplinary health care team



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References

- American Cancer Society (2010). *Cancer Facts and Figures*. Atlanta, GA.
- Bower JE, Ganz PA, Desmond KA, Bernards C, Rowland JH, Meyerowitz BE, & Belin TR (2006). Fatigue in long-term breast carcinoma survivors: A longitudinal investigation. *Cancer*, 106(4):751-758.
- Brotto LA, Heiman JR, Goff B, Greer B, Lentz GM, Swisher E, Tamimi H, & Van Blaricom A (2008). A psychoeducational intervention for sexual dysfunction in women with gynecologic cancer. *Archives of Sexual Behavior*, 37(2), 317-29.
- Campbell HS, Sanson-Fisher R, Taylor-Brown J, Hayward L, Wang XS, & Turner D (2009). The cancer support person's unmet needs survey: Psychometric properties. *Cancer*, 115(14), 3351-3359.
- Chung LK, Cimprich B, Janz NK, & Mills-Wisneski SM (2009). Breast cancer survivorship program: Testing for cross-cultural relevance. *Cancer Nursing*, 32(3), 236-245.
- Elsesser K, van Berkel M, & Sartory G (1994). The effects of anxiety management training on psychological variables and immune parameters in cancer patients: A pilot study. *Behavioural and Cognitive Psychotherapy*, 22, 13-23.
- Hamilton JB, Moore CE, Powe BD, Agarwal M, & Martin P (2010). Perceptions of support among older African American cancer survivors. *Oncology Nursing Forum*, 37(4), 484-493.
- Harrington CB, Hansen JA, Moskowitz M, Todd BL, & Feuerstein M (2010). It's not over when it's over: Long-term symptoms in cancer survivors--a systematic review. *International Journal of Psychiatry in Medicine*, 40(2), 163-181.
- Ganz PA (2005). A teachable moment for oncologists: Cancer survivors, 10 million strong and growing! *Journal of Clinical Oncology*, 23, 5458-5460.
- Golant M & Haskins NV (2008). "Other cancer survivors": The impact on family and caregivers. *Cancer Journal*, 14(6), 420-424.
- Hewitt M, Greenfield S, & Stovall E (2006). *From cancer patient to cancer survivor: Lost in transition*. Institute of Medicine, National Academies Press. Washington, DC.
- Humphris G & Ozakinci G (2008). The AFTER intervention: A structured psychological approach to reduce fears of recurrence in patients with head and neck cancer. *British Journal of Health Psychology*, 13(2), 223-30.
- Kim Y, Kashy DA, Spillers RL, & Evans TV (2010). Needs assessment of family caregivers of cancer survivors: Three cohorts comparison. *Psycho-oncology*, 19(6), 573-582.
- McDowell ME, Occhipinti S, Ferguson M, Dunn J, & Chambers SK (2010). Predictors of change in unmet supportive care needs in cancer. *Psycho-oncology*, 19(5), 508-516.
- Mikkelsen T, Sondergaard J, Sokolowski I, Jensen A, & Olesen F (2009). Cancer survivors' rehabilitation needs in a primary health care context. *Family Practice* 2009; 26: 221-230.
- Redd WH, Montgomery GH, & DuHamel KN (2001). Behavioral intervention for cancer treatment side effects. *Journal of the National Cancer Institute*, 93(11), 810-823.
- Schlairet M, Heddon MA, & Griffis M (2010). Piloting a needs assessment to guide development of a survivorship program for a community cancer center. *Oncology Nursing Forum*, 37(4), 501-508.
- Simpson JS, Carlson LE, & Trew ME (2001). Effect of group therapy for breast cancer on healthcare utilization. *Cancer Practice*, 9, 19-26.
- Yates P, Edwards H, Nash R, Aranda S, Purdie D, Najman J, Skerman H, & Walsh A (2004). A randomized controlled trial of a nurse-administered educational intervention for improving cancer pain management in ambulatory settings. *Patient Education and Counseling*, 53(2), 227-37.

