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Community Interventions for Survivors and Their Families: A Literature Synthesis

Gayle Roux, PhD, RN, NP-C, FAAN, Ann Solari-Twadell, PhD, MPA, FAAN, and Suzanne Ackers, RN, MS

Background: Advancements in technology and treatment have increased the survival rate for many cancers. Because many people in the United States who are living with cancer reside in communities, a need exists for community-based interventions for survivors and their families.

Objectives: The goal of this article is to inform nurses and researchers about current evidence-based community intervention outcomes and make recommendations to support care of community survivors of cancer.

Methods: A literature search was conducted for community interventions with a survivor component. Fifteen articles were selected for analysis in two categories of community intervention research, women with breast cancer and people with all types of cancer.

Findings: The literature synthesis indicated that community-based interventions are beneficial to enhancing quality of life and decreasing symptoms in survivors. Exercise, support, and family-centered interventions for children and spouses demonstrated promising results. These findings have implications for nursing practice in communities, where oncology nurses and other professionals can begin concentrating intervention efforts. Additional studies are needed on high-quality, cost-effective, and collaborative community-based interventions for survivors of cancer, including underrepresented populations.

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Breakthroughs in research, treatment, and technology have increased the survival rate for many types of cancer, accounting for about 14.5 million survivors in the United States (American Cancer Society [ACS], 2015). The National Cancer Institute ([NCI], 2010) estimated that about 15% of these survivors are treated at large cancer centers in the United States and the remaining 85% are treated at local community agencies near where survivors live. About 66% of people with cancer can expect to be alive in five years (NCI, 2011). Eighty percent of survivors of childhood cancer are alive in five years, and their 10-year survival rate is nearing 75% (NCI, 2011). This increase in survivorship has given rise to some identified health risks associated with being a survivor. These health risks affect physical, psychological, spiritual, and psychosocial domains of an individual’s well-being (Centers for Disease Control and Prevention [CDC], 2012). Because the majority of survivors live in homes in communities, resources and strategies inclusive of community interventions should be strengthened within the continuum of care.

The increased survival rate for those diagnosed with cancer has created a shift in the focal point of evidence-based research from prevention and detection efforts to interventions needed to improve and sustain quality of life for survivors and their families (Baker, Denniston, Smith, & West, 2005; CDC, 2012). Increased researcher awareness of this shift toward intervention is demonstrated by the 40% of funded grants that contain some type of intervention component (Rowland, 2011). However, literature on specific types of community-based interventions that have been conducted with survivors and their families is limited. The purpose of this article is to examine...
community-based interventions tailored for survivors and their families and to make recommendations for additional research and practice.

Methods

A comprehensive literature search was conducted using CINAHL®, PubMed, and JSTOR, yielding more than 200 results. Of those results, many were community-based interventions that focused on cancer prevention and detection efforts, leaving about 30 articles that contained a community-based intervention component for survivors. Key search terms included variations of cancer, community-based interventions, children in the home, cancer interventions, spouses, cancer survivors, and survivorship. The literature search was limited to articles published from 2004–2013. Abstracts were reviewed for evidence that a systematic inquiry format classified as research was used. Only research articles with community-based interventions for survivors and their families were selected for review. This search strategy resulted in the selection of 15 articles for review (see Table 1).

Survivor Risks

A cancer diagnosis rapidly affects the quality of life and distress level of survivors and their families. A person becomes a survivor at the moment of diagnosis and remains one throughout the remaining years of his or her life (Bell, 2010). As children and adult survivors live longer and research studies supported by NCI continue to mature, risk factors are emerging that reveal a gap in evidenced-based research in the area of interventions aimed at reducing survivor risks (Rowland, 2011). A wealth of information is available on community-based intervention efforts aimed at cancer prevention and detection, but minimal research is available on the topic of community-based interventions geared toward survivors and their families (Baker et al., 2005; Lewis, Casey, Brandt, Shands, & Zahlis, 2006; Lewis et al., 2007; Stiffler, Haase, Hosei, & Barada, 2008). This deficiency indicates a need for implementation of community-based interventions to decrease the identified risks associated with survivorship (NCI, 2012).

The Behavioral Risk Factor Surveillance System (BRFSS), established in 1984 by the CDC, is a state-based telephone survey of the noninstitutionalized U.S. population that collects monthly information on health risk behaviors, preventive health practices, and access to health care as it relates to chronic disease and injury. In the 2009 CDC report on the BRFSS, physical risks associated with being a survivor included the presence of comorbidities, such as diabetes and cardiovascular disease, coupled with cigarette smoking, a lack of exercise, and obesity (CDC, 2012). Sleep disturbances and sexual dysfunction were among other areas of physical complaints described by survivors (Baker et al., 2005). Community-based interventions that concentrate efforts on confronting these health issues have the potential to increase quality of life for survivors and their families.

Fear of the unknown and of recurrence is a frequent psychological hurdle to overcome for survivors and their families (Baker et al., 2005; Dingley & Roux, 2014; Semple & McCance, 2010; Stiffler et al., 2008). A cancer diagnosis can create feelings of fear and insecurity that, without intervention from oncology nurses or community-based nurse collaborators, could lead to increased distress for survivors and their families. Implementation of community-based programs and support services have the potential to help alleviate anxiety and improve quality of life (Baker et al., 2005; Hawkes, Hughes, Hutchison, & Chambers, 2010; Helseth & Ulfsaet, 2005; Lu, Zheng, Young, Kagawa-Singer, & Loh, 2012; Rogerino, Grant, Wilcox, & Schmitz, 2009).

The psychosocial aspects vary based on many factors, such as the survivor’s age, stage of life at which cancer occurred, communication preferences, and personal strength-building strategies (Baker et al., 2005; Boesen et al., 2011; Coyne, Lepore, & Palmer, 2006; Dingley & Roux, 2014; Roux & Dingley, 2005, 2011). A cancer diagnosis has the potential to provoke a host of changes (e.g., depression, fatigue, changes in social and work relationships) that can lead to a negative state of well-being. A series of literature findings indicate that, although meeting psychosocial needs is important in maintaining quality of life and positive well-being, individual preferences for the type and setting of support vary. Some studies have found that group psychotherapy does not decrease distress levels for survivors (Boesen et al., 2011; Coyne et al., 2006; Kissane et al., 2004). Other studies demonstrate that survivors prefer interventions that involve support and communication from individual, trusted healthcare providers rather than from a group therapy setting (Baker et al., 2005; Hawkins et al., 2010; Helseth & Ulfsaet, 2005). Whether group therapy and counseling interventions would be sustainable in the community is unclear because the efficacy of many group therapy mechanisms has not been well studied (Coyne et al., 2006).

NCI defined spirituality as “having to do with deep, often religious, feelings and beliefs including a person’s sense of peace, purpose, connection to others, and beliefs about the meaning of life” (Skalla & McCoy, 2006, p. 745). Others have defined spirituality as more distinct from religion. Burkhart and Solari-Twadell (2001) defined spirituality as “the experience of and integration of meaning and purpose in life through connectedness with self, others, art, music, literature, nature, or a power greater than oneself” (p. 49). Survivors may become isolated and disconnected from their self, others, and their community during treatment. This disconnect has the potential to contribute to the already vulnerable state of themselves and their families, creating spiritual distress (Dingley & Roux, 2014). Spiritual care is a necessary component in caring for the whole person surviving cancer. Spirituality crosses cultures and faiths to provide a common ground for dialogue between survivors, their families, and community-based care providers (Skalla & McCoy, 2006).

Patient time costs (i.e., the time factor associated with receiving treatments and visiting healthcare providers) can be substantial, depending on the cancer type, stage of diagnosis, and treatment (Yabroff et al., 2007). Financial and patient time costs may be overlooked in the care of survivors. Survivors may be subject to denial of different types of insurance or high costs for coverage (Baker et al., 2005). The burden of monetary and patient time costs for survivors can lead to interruptions in the flow of everyday life, potentially causing additional physical and psychological distress.
TABLE 1. Literature Review of Community Interventions for Survivors of Cancer

<table>
<thead>
<tr>
<th>Study</th>
<th>Focus</th>
<th>Methods</th>
<th>Findings</th>
<th>Recommendations</th>
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<tbody>
<tr>
<td>Badr et al., 2010</td>
<td>Dyadic coping in metastatic breast cancer</td>
<td>Surveys at start of treatment and at three and six months; Impact of Events Scale and short form of the Dyadic Adjustment Scale</td>
<td>More couple-focused interventions are needed in which the partners' needs are addressed along with the patients' needs.</td>
<td>More couple-focused interventions that concentrate on adaptive coping and learning how different cultures cope with stress.</td>
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<td>Baker et al., 2005</td>
<td>Psychosocial problems affecting survivors</td>
<td>752 patients from three states, one year after diagnosis; Pilot Study of Cancer Survivors—I; questionnaire using the Cancer Problems in Living Scale</td>
<td>Psychological finding: fear regarding diagnosis and the future Physical finding: fatigue, loss of strength, and sexual dysfunction</td>
<td>Public health programs that incorporate counseling and support services to help survivors deal with fears and emotions.</td>
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<td>Boesen et al., 2011</td>
<td>The effectiveness of a psychoeducational group therapy intervention to improve distress and QOL for patients with breast cancer</td>
<td>Randomized trial using several scales, including Profile of Mood States, Total Mood Disturbance Scale, and European Organisation for Research and Treatment of Cancer QOL Questionnaire–Core 30</td>
<td>No statistically significant effects of the intervention were found. The only significant result was for patients who also were taking antidepressive medications.</td>
<td>Integrate a physical activity regimen and screening for depressive symptoms into cancer survivorship care.</td>
</tr>
<tr>
<td>Coyne et al., 2006</td>
<td>Psychosocial interventions for cancer</td>
<td>RCTs for efficacy of psychosocial interventions published in high-impact journals</td>
<td>Patients with cancer are more concerned with receiving support and communication from healthcare providers than counseling.</td>
<td>Future RCTs should compare outcomes with oncology professionals trained in tailored psychosocial interventions to usual care.</td>
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<td>Hawkes et al., 2010</td>
<td>Community-based psychological distress screening for patients with cancer and their caregivers</td>
<td>Telephone helpline from September to December 2006; used the Distress Thermometer to detect psychological distress. Callers were triaged to an appropriate level of supportive care using a tiered model.</td>
<td>64% of patients with cancer and 90% of caregivers were distressed. All callers to the helpline could be triaged to an appropriate level of care.</td>
<td>A brief distress screening by a community-based cancer helpline may help bridge the treatment gap, ensuring that those who are distressed by cancer are identified and the supportive level of care is provided.</td>
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<td>Hawkins et al., 2010</td>
<td>Mediating processes of two communication interventions for newly diagnosed patients with breast cancer</td>
<td>RCT testing four interventions: (a) Internet training, (b) integrating CHESS eHealth Breast Cancer Support, (c) having a phone conversation with a mentor, and (d) combining interventions (a) and (b); measured using the World Health Organization QOL assessment</td>
<td>Women who received information from CHESS and phone calls from a human cancer information mentor had higher QOL.</td>
<td>This study can be applied to other diseases, not just breast cancer.</td>
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<tr>
<td>Helseth &amp; Ulfsaet, 2005</td>
<td>Parenting experiences of patients with cancer and their spouses with children</td>
<td>Explorative design; interviews with a convenience sample of 18 parents in 10 families from 2001–2002</td>
<td>The overall aim for parents was to protect their children and make the illness situation as secure and normal as possible for the children. The parents focused on trying to maintain normalcy as family priorities changed during treatment. Parents valued close communication with their children.</td>
<td>Parental guidance programs need to be developed and introduced into clinical and community settings.</td>
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<tr>
<td>Lewis et al., 2006</td>
<td>Enhancing Connections Program, a cognitive-behavioral intervention for mothers and children affected by breast cancer</td>
<td>The program involves five one-hour educational counseling sessions delivered at two-week intervals by a trained clinician. Thirteen households were recruited for the study.</td>
<td>Significant improvement in mothers' depressed mood, anxiety, and self-confidence to assist their children, and decreases in children's behavioral problems, cancer-related worries, anxiety, and depressed mood</td>
<td>Additional evaluation is warranted with a clinical trial, which has been funded by the National Institutes of Health.</td>
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CHESS—Comprehensive Health Enhancement Support System; RCT—randomized clinical trial; QOL—quality of life

(Continued on the next page)
TABLE 1. Literature Review of Community Interventions for Survivors of Cancer (Continued)

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<td>Lewis et al., 2007</td>
<td>Helping Her Heal Program, a five-session counseling intervention for spouses of women with breast cancer with the goal of enhancing spouses' communication and support skills</td>
<td>20 spouses were recruited. Pre- and post-study questionnaires were used, including Center for Epidemiological Studies—Depression and Cancer Self-Efficacy Scale—Spouse.</td>
<td>Significant improvements in spouses’ depressed mood, anxiety, skills, self-confidence, and self-care</td>
<td>Additional evaluation is warranted with a clinical trial.</td>
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<td>Lu et al., 2012</td>
<td>Asian American survivors of breast cancer</td>
<td>Community-based participatory research approach. A baseline questionnaire was obtained, and writing instructions to follow for a three-week period and then a health outcomes questionnaire were sent.</td>
<td>Expressive writing is associated with long-term improvement of health outcomes and may have the potential to be used by other underserved populations.</td>
<td>Additional studies using randomized trials with diverse populations of survivors are needed.</td>
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<td>Mutrie et al., 2007</td>
<td>Functional and psychological benefits of a 12-week supervised exercise program for women with early-stage breast cancer, with six-month follow-up</td>
<td>Pragmatic, randomized, controlled, prospective, open trial; used the Functional Assessment of Cancer Therapy questionnaire, Beck Depression Inventory, Positive and Negative Affect Schedule, and body mass index</td>
<td>Supervised group exercise provided functional and psychological benefit after 12 weeks and after six months.</td>
<td>Policymakers should consider including exercise opportunities in cancer services.</td>
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<td>Rajotte et al., 2012</td>
<td>The effectiveness and safety of a disseminated community-based exercise program for survivors who have completed treatment</td>
<td>Used YMCA personal trainers; 12-week group sessions. Assessment measures included patient-reported outcomes and physiologic measurements.</td>
<td>Community-based exercise groups for survivors who have completed treatment and are of mixed diagnoses and ages have physical and psychological benefits and are safe.</td>
<td>Use cancer registries to recruit diverse populations of survivors.</td>
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<tr>
<td>Rogerino et al., 2009</td>
<td>Geographic recruitment of survivors of breast cancer in community-based exercise interventions</td>
<td>Modification of the Physical Activity and Lymphedema Trial; letters sent to specific ZIP codes in cooperation with state cancer registries</td>
<td>State cancer registries are a useful tool to recruit racially and geographically diverse survivors of breast cancer into a community-based exercise intervention. This study supports the goal of conducting health behavior interventions within communities where survivors live.</td>
<td>Other forms of recruitment (e.g., flyers, media, hospital registries, support groups), although not the most effective means of recruitment, are vital to the success of dissemination.</td>
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<tr>
<td>Semple &amp; McCance, 2010</td>
<td>Experience of parents with cancer who are caring for young children</td>
<td>Literature review</td>
<td>Three parent-experience themes emerged: being a good parent, communicating with children, and maintaining routine at home.</td>
<td>Support for parents with cancer on relevant parenting issues should be acknowledged.</td>
</tr>
<tr>
<td>Stiffler et al., 2008</td>
<td>Maternal parenting from the mother’s and adolescent daughter’s perspectives after the mother has been diagnosed with breast cancer</td>
<td>Empirical, phenomenologic approach using open-ended, audio-recorded interviews</td>
<td>Mothers set a high priority on parenting and meeting their own needs and those of their adolescent daughters.</td>
<td>Mothers should be given assistance with strategies for setting priorities. Additional research should focus on resuming effective parenting once the mothers’ treatments are complete and normalcy in survivorship.</td>
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CHESS—Comprehensive Health Enhancement Support System; RCT—randomized clinical trial; QOL—quality of life
Community-Based Interventions

Interventions in the community have the potential to lead to favorable outcome for survivors. Community-based interventions have five predominant themes: (a) support services for survivors and their families, (b) variance in survivor interest in different types and settings for support, (c) exercise, (d) disparate integration of minority affected populations, and (e) lack of inclusion of spiritual interventions. In general, a consistent theme noted in the literature review was that efficacy studies and recruitment of survivors for community interventions require additional research.

Theme 1: Support Services

The literature describes a wide range of support services that have the potential to be used successfully with survivors and their families, including children. These include those aimed at improving communication and coping (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Helseth & Ulfsaet, 2005; Lewis et al., 2006, 2007; Semple & McCance, 2010; Stiffler et al., 2008; Tercyak, Mays, DeMarco, Sharff, & Friedman, 2012). Technology is an increasingly common medium to educate, mentor, and decrease distress in survivors and their families (Hawkes et al., 2010; Tercyak et al., 2012). For example, Hawkes et al. (2010) implemented a three-month study using a telephone helpline that used the Distress Thermometer to help detect psychological distress. Callers were screened using the Distress Thermometer and then were triaged to an appropriate level of care using a tiered model of care. Hawkes et al. (2010) found that 64% of survivors and 90% of caregivers were distressed and could be triaged successfully in the community. In a study on home interventions directed to mothers with breast cancer and their school-aged children, Lewis et al. (2006) implemented five one-hour educational sessions delivered at two-week intervals by specially trained clinicians. The intervention, the Enhancing Connections Program, was found to significantly improve mothers' depressed mood, anxiety, and self-confidence to care for their children (Lewis et al., 2006).

Expressive writing was another community-based intervention found to help survivors cope with their feelings and emotions associated with cancer. The task of writing feelings can improve quality of life, physical health, and spiritual and psychological adjustment. Expressive writing has been shown to improve well-being and affect among non-Hispanic Caucasian survivors of breast cancer. Writing also is felt to help overcome cultural and linguistic barriers. Lu et al. (2012) found that this strategy also was successful when implemented with Chinese-speaking survivors of breast cancer.

Theme 2: Variance in Types and Settings

Studies have indicated that community interventions that focus on psychoeducational group therapy are less effective in decreasing distress and improving overall quality of life for survivors (Boesen et al., 2011; Coyne et al., 2006). Survivors reported that they were less interested in coming together in a psychoeducational group and preferred individually tailored counseling or mentorship focused on their unique set of needs (Boesen et al., 2011; Coyne et al., 2006). Evidence supports the need for community counseling programs to help survivors cope with fear, negative emotions, and the physical effects of cancer (e.g., decreased sexual dysfunction, fatigue) (Baker et al., 2005). For example, community health programs that incorporate counseling and mentorship programs using a human cancer information mentor, a trained specialist with individualized interventions in cancer support, have been shown to benefit survivors and their families in managing physical and psychological challenges and improving community reintegration (Hawkes et al., 2010).

Theme 3: Exercise

Implementation of a healthy exercise regimen has been demonstrated to benefit survivors. Exercise has been shown to increase quality of life and overall physical and psychological well-being, whether survivors are enduring the early stages of treatment or are in a state of remission (Mutrie et al., 2007; Rajotte et al., 2012; Rogerino et al., 2009). The importance of physical exercise at any stage of survivorship makes this intervention an important component in community-based programs. For example, using community organizations to house exercise programs for survivors can enhance dissemination efforts because these establishments can be found in communities nationwide (e.g., Livestrong at the YMCA).

Theme 4: Disparate Integration of Minority Affected Populations

Little mention was made of community-based interventions with minority populations (e.g., African Americans, Hispanic populations) or inclusion of diverse family members (e.g., gay, lesbian). However, statistics reveal a substantial impact on these minority groups regarding cancer diagnosis and mortality (ACS, 2015). These populations also may have less access and fewer resources than other racial groups or traditional family members (ACS, 2015). Only one article included the effects on extended family members (e.g., parents or grandparents of parents diagnosed with cancer) (Helseth & Ulfsaet, 2005). With roles and relationships changing as family members adjust to the reality of cancer, not only are children and spouses affected, but also extended family members and same-sex partners.

Theme 5: Lack of Inclusion of Spiritual Interventions

One article included perspectives on the spiritual care of survivors (Skalla & McCoy, 2006). Many survivors are members of faith communities. Prayer and corresponding rituals are important coping strategies that support a healthy existence with a chronic disease. Faith community nurses often can be excellent collaborators with oncology nurses in reinforcing healthy lifestyle choices. Faith community nursing, originally called parish nursing, is defined as “care that supports and facilitates physical functioning, psychological functioning, and lifestyle change with particular emphasis on coping assistance and spiritual care; protection against harm; the family unit; effective use of the health system and health of the congregation and community” (Solari-Twadell & Hackbarth, 2010, p. 74). Seeking congregations that include the service of a faith...
community nurse can aid in extending support for survivors and their families.

Implications for Oncology Nursing

Oncology nurses are in a position to facilitate community-based interventions for survivors and their families. Nurses should consider a few key implications when implementing interventions in the community, based on the five themes found in the literature review. Community-based intervention support measures should be specific to certain populations of survivors based on their stage of life, treatment, and personal preferences for support interventions. Community-based counseling or mentor services that focus on the individual needs of survivors and their families have the ability to improve overall quality of life. Exercise programs in the community have been reported to benefit survivors’ health and well-being. Personal spirituality for survivors and their families should be emphasized as part of the overall care plan. As advancements have improved cancer outcomes and survivorship, technology also plays a role in access to health services and enhanced well-being. Individualized community-based interventions that focus on support measures for specific populations of survivors based on the survivors’ age, preferences, and family hold promise for positive outcomes. Exercise programs for survivors should be made available within the community through local YMCAs, churches, schools, and community centers, because this intervention has demonstrated a positive outcome in the research studies. Research is needed on community-based interventions that include diverse populations, with an increased concentration on the mentorship role, spirituality, and support measures for the individual, extended family members, and same-sex partners.

Conclusion

The five-fold increase in survivors since the 1970s urges examination of economic factors related to the dissemination and sustainment of interventions at the community level (Rogerino et al., 2009). For example, an identified barrier is whether survivors have financial means and access to transportation to intervention locations (Mutrie et al., 2007; Rajotte et al., 2012; Rogerino et al., 2009). Roux et al. (2008) conducted a study on the cost effectiveness of community-based physical exercise interventions related to five diseases, including breast and colorectal cancers. The study revealed that cost-effectiveness ratios ranged from $14,000–$69,000 per quality-adjusted life-year of the overall U.S. national expenditure of $24–$76 billion spent annually on health consequences related to inactivity (Roux et al., 2008). Policymakers and advocates should consider the inclusion of community-based exercise programs as a means of cancer rehabilitation in much the same way as patients with cardiac disease receive cardiac rehabilitation (Mutrie et al., 2007; Roux et al., 2008).

Areas for additional research lie in determining the most cost-effective, high-quality community-based interventions. Using community social centers, churches, hair salons, and local workout facilities can be helpful in bringing information on types of community-based intervention programs to survivors. Additional studies are needed on cultural components of specific interventions to reach out to survivors in understudied populations and extended or nontraditional family systems. Expressive writing is a strategy to consider implementing at a community-based level because writing is economical and could be performed at home. The role of faith community nurses in supporting spiritual health and overall well-being of survivors and their families needs to be explored in more depth. In addition, the financial burden of cancer, coupled with the associated patient time cost, can lead to many physical and psychological issues and requires additional studies. Community interventions that are economical, connected to the survivors’ home community, and representative of diverse populations of survivors and their families are needed to advance the cancer care trajectory.

References


