Impact of a Community-Based Cancer Survivorship Program on Quality of Life

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Despite the demonstrated need to implement evidence-based interventions that address the psychosocial and behavioral concerns of cancer survivors, few studies have evaluated the effectiveness of community-based survivorship programs. To address this need, the Fort Worth Program for Community Survivorship—a community-based cancer survivorship program at the University of Texas Southwestern Medical Center Moncrief Cancer Institute in Fort Worth, Tex.—conducted a study involving more than 200 post-treatment cancer survivors to evaluate the effectiveness of the program's services.

The Fort Worth Program for Community Survivorship aims to address the unmet psychosocial needs of cancer survivors with one-on-one attention, assessment, and referral. This study examined the extent to which the program was able to reduce psychological distress and improve quality of life (QoL) among cancer survivors and the degree to which individual program participation predicted enhanced psychosocial functioning.

The 203 post-treatment cancer survivors who participated in the study program received psychosocial and behavioral services, including exercise, dietary consult, and psychological counseling. Program participants were evaluated upon enrollment and at three subsequent intervals. Outcomes demonstrated an association between program participation and significant improvements in both QoL and distress relief, with the largest improvements occurring during the first three months of program participation, when participant attendance was highest.

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A Need for Data

The number of cancer survivors in the United States is projected to grow to nearly 18 million by 2022, increasing more than 30 percent in just 10 years.[1] The growing body of literature on the pervasive negative effects of cancer and its treatment frequently cites emotional health and well-being among the areas of highest need among post-treatment cancer survivors.[2,3] Nearly one-third of cancer survivors report deterioration of physical and/or mental functioning up to four years post-diagnosis, and approximately 37 percent note increased psychological impairment and/or specific unmet needs years following treatment.[4,5]

Some psychological issues are not apparent until many years after treatment; long-term cancer survivors face fear of recurrence, financial concerns, difficulties with sexual health, poor emotional functioning, and adverse late-term effects of treatment.[6,7] In response, specialized, multidisciplinary programming has emerged to address cancer survivors' needs. However, most survivorship programs are restricted to large, academic-based settings, even though approximately 55 percent of cancer patients receive their medical care in community oncology settings.[8,9]

Most of the existing literature on survivorship programming focuses on building (rather than evaluating) programs.[10-12] Few studies have examined patient-reported psychosocial outcome data from cancer survivorship programs, and even fewer have focused on outcomes within real-world, community-based programs. There is a need to understand how evidence-based interventions are used by cancer survivors and how well they work.

Our evaluation of the Fort Worth Program for Community Survivorship reflects a "pragmatic" method, defined as the flexible delivery of interventions and conditions relevant to real-world clinical practice.[13] The Fort Worth Program uses a patient-centered approach to intervention; after the initial assessment, participants choose the types and intensity of the interventions they want based on their needs and preferences. To gauge the effectiveness of the interventions, we measured longitudinal QoL and psychosocial distress outcomes.

Program Overview

Study participants included 203 post-treatment cancer survivors who had enrolled in the Fort Worth Program for Community Survivorship for psychosocial and behavioral survivorship services. These adults, aged 18 and older, completed their primary cancer treatment in the community setting. For the purposes of this study, we made special efforts to include underserved and uninsured individuals in the program.[14] Participants were either self-referred to the program or they were referred by local hospitals, clinics, and agencies.

Once study participants were referred to the Fort Worth Program for Community Survivorship, program staff contacted them by phone to set up an initial appointment and gather basic demographics. At that first in-person visit, all participants received a survivorship portfolio, which contained general and targeted information about their diagnosis, treatment side effects, and post-treatment care. Participants also met with a registered nurse who oriented them to the program, conducted a basic history and physical, and discussed their current psychosocial needs based on their medical history and responses to questionnaires they completed prior to the initial visit.

Based on identified needs and individual preferences, the nurse then assisted with referrals to evidence-based services, including appointments with psychologists, social workers, dietitians, oncology exercise specialists, genetic counselors, a financial advocate, a pain physician specialist, a lymphedema specialist, and a fatigue specialist.

All survivorship services were available to participants at no charge or for a reduced fee except for pain-, lymphedema-, and fatigue-specific services, which were provided through referrals to off-site providers. Study consent and enrollment occurred at the first visit, and enrolled participants agreed to complete self-reported assessments at baseline and at 3-, 6-, and 12-month intervals post-enrollment. This analysis focuses on psychological distress and QoL data from each of these study time points.

Participants

A total of 291 program participants were approached about completing longitudinal measures, and 205 (70.4 percent) consented to participate. There were no significant differences in age, gender, race/ethnicity, marital status, education level, or language preferences among those who consented and those who declined to complete the measures. One participant withdrew before completing baseline questionnaires, and another did not complete psychosocial measures at any time point.

Thus, a total of 203 participants were included in the final analyzed sample. Table 1, below, displays participant sample size and retention rates at each time point for both outcome measures. The largest drop-off in response occurred between baseline and the 3-month follow-up, with lower attrition in the later follow-up time points (6 and 12 months). As detailed in Table 2 (right), the sample was predominantly female, with approximately one-third identifying as racial or ethnic minorities.

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Table 1. Sample Size at Each Time Point

Measures	Baseline (*N*)	3 Months *N* (% of Previous Time Point)	6 Months *N* (% of Previous Time Point)	12 Months *N* (% of Previous Time Point)
BSI-18	203	144 (71%)	125 (87%)	113 (90%)
FACT-G	203	141 (69%)	125 (89%)	113 (90%)

Table 2. Descriptive Demographic and Illness Data (*n* = 203)

Source	Mean (SD) or *n* (%)	Source	Mean (SD) or *n* (%)
Demographics		**Illness characteristic**	
Age (years), mean (SD)	56.7 (9.7)	Time since diagnisis (years)	3.6 (4.9)
Gender		**Primary cancer location**	
Female	177 (87.2)	Breast	147 (72.4)
Race/Ethnicity		Prostate	10 (4.9)
Non-Hispanic white	138 (68.0)	Head and Neck	7 (3.4)
Non-Hispanic black	31 (15.3)	Colorectal	8 (3.9)
Hispanic	28 (13.8)	Lung	4 (2.0)
Asian	1 (0.5)	Gynecological	7 (3.4)
Multiracial	2 (1.0)	Lymphoma	4 (2.0)
Other	2 (1.0)	Other	16 (7.9)
Unknown	1 (0.5)	**Cancer stage**	
Marital Status		0	12 (5.9)
Married	109 (53.7)	I	57 (28.1)
Divorced	41 (20.2)	II	64 (31.5)
Widowed	11 (5.4)	III	34 (16.7)
Separated	2 (1.0)	IV	7 (3.4)
Never married	36 (17.7)	Unknown	29 (14.3)
Unmarried couple	4 (2.0)	No history of recurrence/second cancer	179 (88.2)
Education level		**Treatment type**[1]	
Grades 9-11	4 (2.0)	Chemotherapy	133 (65.5)
Grade 12 or GED	38 (18.7)	Radiation	102 (50.2)
Some college/tech shoool	77 (37.9)	Surgery	162 (79.8)
College graduate or higher	82 (40.4)	**Comorbid symptom burden**[2]	
Unknown	2 (1.0)	Low	46 (22.7)
Preferred language		Medium	81 (39.9)
English	191 (94.1)	High	76 (37.4)
Spanish	12 (5.9)	Karnofsky performance status (median)[4]	100
DIstance from clinic in miles, mean (SD)[3]	12.2 (13.9)		

[1] *n* = 203; patients could receive more than one treatment modality.

[2] Based on the number of self-reported concerns on a confidential health questionnaire.

[3] *n* = 199, because distance was not able to be calculated for four participants.

[4] *n* = 197; a Karnofsky performance status score was not assigned to six participants.

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Explanation of Measures

The dependent variables used in this study included the Brief Symptom Inventory (BSI-18)—a well-validated, 18-item self-report assessment of psychological distress that has been recommended for use in oncology populations.[15,16] This inventory—a Likert-type scale, ranging from 0 (*not at all*) to 4 (*extremely*)—measures how much a respondent has been bothered by distress-related behaviors and symptoms during the past week. The measure provides a total score—termed the Global Severity Index—as well as scores on three subscales—Somatization, Depression, and Anxiety—with higher scores indicating greater distress.

To measure QoL, we used the Functional Assessment of Cancer Therapy-General (Version 4; FACT-G), which—like the Brief Symptom Inventory—uses 27 items rated on a 5-point Likert-type scale ranging from 0 (*not at all*) to 4 (*very much*).[17] This measure contains four subscales representing physical, functional, social/family, and emotional well-being in addition to an overall score. Higher scores indicate better QoL.

Sociodemographic information was self-reported by the participants and included age, sex, language preference, education level, marital status, race/ethnicity, and ZIP code. We also collected information on illness characteristics—including primary cancer diagnosis, history of recurrence or multiple cancers, cancer stage, time since diagnosis, Karnofsky performance status,[18] and treatment history—through a combination of self-reporting and medical chart review.

Table 3. Service Utilization Summary

Service Type	Total Number of Visits	*n*	Mean	SD
Exercise	1,994	178	11	9.8
Nutrition	237	118	2	1.7
Nursing	203	203	1	0.0
Social work	117	112	1	0.2
Psychology	252	43	6	4.5
Pain management	1	1	1	0.0
Genetic counseling	6	6	1	0.0
Financial advocacy	5	5	1	0.0
All service types	2,815	203	13	10.6

We computed the level of comorbid symptom burden (low, medium, or high) from information provided in the "Review of Symptoms" section of a confidential health questionnaire that participants completed prior to enrollment. We recorded information about service utilization—defined as participant attendance at program services and the type of service provided—for each participant during the 12 months after enrollment.

Service Utilization

Table 3, below, displays the total number of service visits attended by program participants broken down by service type. Participants attended 2,815 multidisciplinary service appointments, which included encounters with psychology, genetic counseling, social work, nutrition, individual exercise, nursing, pain management, and financial advocacy professionals. As mentioned previously, all participants received an initial nurse assessment (included in the total count of appointments reported above) as part of the orientation to the program; this assessment was completed during at least one in-person visit.

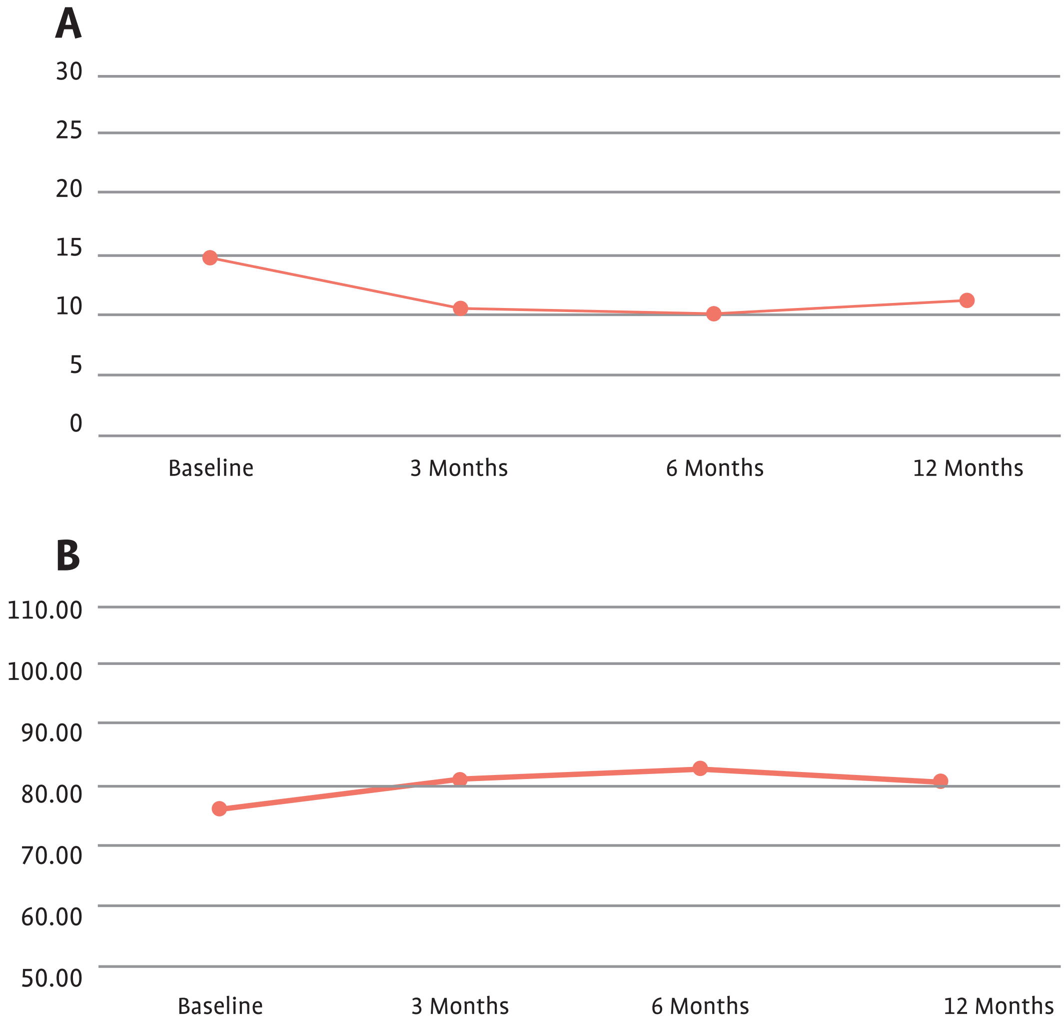
One hundred ninety-five participants (96.1 percent) completed at least one additional service appointment beyond the initial nurse assessment, with participants completing a median of 13 encounters across the various disciplines. Exercise was the most frequently attended service, with 87.7 percent of all study participants attending at least one individual exercise session. The majority of service utilization (76.6 percent) occurred within the first 3 months of participant enrollment, 12.5 percent of appointments occurred between 3 and 6 months of enrollment, and 10.8 percent occurred between 6 and 12 months after enrollment.

Results: Change in Psychosocial Functioning over Time

Physical and emotional well-being displayed a significant change over time, with respective improvements for each month of program enrollment. Figure 1, right, displays unadjusted raw scores and standard deviations for the BSI-18 Global Severity Index and the FACT-G Total Score at each time point. Significant improvements in both transformed QoL and distress scores were observed over time, with scores decreasing for each month of enrollment. These findings suggest significant improvements in both QoL and psychological distress among participants across the 12-month intervention period. Our analysis of reported data also revealed:

- The number of participants with below-average QoL decreased from nearly half (49 percent) to approximately one-third (37 percent), showing that participants' QoL significantly improved during the 12-month period following enrollment in the community-based survivorship program, with most notable gains during the first 3 months of study participation. This pattern of improvement mirrors participants' involvement with the program, because nearly three-fourths of all services were received during the first 3 months of enrollment.

Figure 1. Unadjusted Raw Scores and Standard Deviations for (A) Distress (BSI-18 Global Symptom Index) and (B) Quality of Life (FACT-G Total Score) for the Overall Sample ($n = 203$) at Each Study Time Point. Decreases in Distress Scores and Increases in Quality of Life Scores Reflect Improvements in These Domains, Respectively



- As with QoL scores, findings suggest that distress improved the most during the first 3 months of study participation and remained significantly lower than baseline scores throughout the study. Though 73 percent of the study sample were highly distressed at baseline, this proportion dropped to 61 percent, 56 percent, and 55 percent at 3, 6, and 12 months, respectively.
- Reported anxiety scores decreased each month. Program participation may better target anxiety-related distress symptoms than other aspects of distress and may promote emotional, physical, and perhaps functional QoL.
- Changes in functional well-being scores, though not significant, indicate a trend toward improvement over time.
- Social/family well-being scores remained relatively stable with no significant change over time.

Total service utilization did not significantly impact the rate of change in psychosocial outcomes over time. Regardless of the number of appointments attended, participants' QoL and distress improved at the same rate. All participants in the study received a considerable amount of both generalized and targeted information about cancer survivorship at enrollment. Combined with the individualized attention of supportive care staff familiar with the needs of cancer survivors, this information may have been sufficient to foster sustained improvement over time.

These results suggest that relatively brief survivorship care may help improve psychosocial functioning by normalizing and validating patients' experiences while also providing useful information on navigating the survivorship phase of cancer care.

Further research is needed to better understand the nature and mechanisms of psychosocial change experienced by program participants and its consequences on longer-term survivorship outcomes, including behavioral change, cancer surveillance, and recurrence.

Study Limitations

One of this study's strengths was its pragmatic design, which allowed for program evaluation in routine practice conditions. This design is common in dissemination and implementation studies, in which goals focus on real-world clinical settings.[19] However, because the study design did not include a comparison group, it is difficult to determine whether overall improvements better reflect increasing time since diagnosis or intervention effects. In fact, results from non-interventional studies show natural declines in distress and recovery of QoL over the first year of cancer survivorship.[20,21]

However, the current study sample included greater heterogeneity in the time since diagnosis, as most individuals (70 percent) enrolled beyond their first year post-treatment, when change is less common.[7] Although participants may have improved over time regardless of receiving an intervention, the current findings suggest that participation in survivorship programming may enhance psychosocial improvement, especially for individuals beyond one year post-treatment.

Although recruitment efforts for the survivorship program focused on enrolling underserved participants, the majority of the study sample was female, non-Hispanic white, college educated, and included survivors of breast cancer, limiting study generalizability. Data from the U.S. Census Bureau suggest that the population living in Tarrant County (location of the Fort Worth metropolitan area) is mostly non-Hispanic white (76 percent) and educated (85 percent with at least a high school education).[22] Our sample may be representative of the area, despite the higher proportion of female participants. Additionally, the composition of the study sample may represent the types of individuals who are interested in and able to attend survivorship services, especially given the evolving and deliberate recruitment strategies of the program.

Conclusions

This analysis is among the first to examine patient-reported outcomes among a group of cancer survivors enrolled in a community-based cancer survivorship program. By characterizing the trajectory of both QoL and psychological distress during participation, this study sheds light on the ability of cancer survivorship programs to improve psychosocial functioning. Chiefly relevant to clinical application, results suggest that a little intervention goes a long way, as evidenced by clinically significant improvements in psychosocial functioning early in program participation.

This recommendation may be particularly helpful for survivorship programs with limited resources and capital, as well as for cancer survivors with time constraints. Further research is needed to better understand the nature and mechanisms of psychosocial change experienced by program participants and its consequences on longer-term survivorship outcomes, including behavioral change, cancer surveillance, and recurrence.

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Disclosure of Interest

Dr. Jeffrey Kendall is on the Speaker Bureau for both Lilly Oncology and Novartis Oncology. All other authors report no potential conflicts of interest.

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