

Quality of Life and Life Engagement for Participants in a Community-based Integrative Therapy Program for Cancer Survivors: *Partners in Wellness*

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Partners in Wellness and Dickinson College

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Background

There are estimated to be 12 million cancer survivors in the US. (Altekruse *et al.*, 2010). People with cancer must deal with its effects both during and post-treatment. Fatigue and pain may persist after treatment (Dow, *et al.*, 1996). Other post-treatment consequences may include sexual problems, body-image and appearance concerns (Ferrell *et al.*, 1995), and psychological dysfunction (Gotay & Muraoka, 1998). As a result, programs to enhance cancer survivors' *quality of life* have proliferated.

Partners in Wellness

Partners in Wellness is unique in being community based. Unlike many programs for survivors, it is unaffiliated with a cancer center but is housed in a YWCA and funded by community nonprofit organizations. Since 2004, about 250 individuals (both women and men) have participated for up to 36 months after cancer treatment. Participants generally attend a fixed number of pre-funded sessions and may continue as fee-paying clients.

Partners staff includes an RN certified to teach yoga, and certified practitioners of Reiki and massage. This study was conducted to provide both standardized and qualitative evaluation data to the *Partners* program.

Quality of Life

Quality of life refers to a multifaceted state of well-being. It includes ability to perform everyday activities and satisfaction with one's level of functioning (Gotay *et al.*, 1992). Thus, it has physical, emotional, psychological, and interpersonal components (Avis *et al.*, 2006) and should be measured accordingly. The Quality of Life in Adult Cancer Survivors (QLACS; Avis *et al.*, 2005) scales evaluate individuals' quality of life based on five cancer-specific and seven general domains. These were used as standardized measures for the study.

Life Engagement

Pursuing valued goals enables us to remain engaged with life and see it as purposeful (Scheier *et al.*, 2006). Such life engagement clearly relates to quality of life. The Life Engagement Test (LET; Scheier *et al.*), a 6-item self-rating scale that has been validated on cancer survivors, was another standardized measure.

Study Objectives

1. Assess the appropriateness and functioning of QLACS and LET for *Partners* participants, to decide whether these standardized measures should be incorporated in future program evaluations.
2. Examine relationships between these measures and health status indicators.
3. Obtain and interpret reflective comments about the program, including participants' most memorable experiences, their descriptions of program activities or concepts that still are used in daily life, and accounts of the most important lessons learned in the program.



Bonnie Berk (far right) leads a *Partners* yoga class

Methods

This single-group study was approved by Dickinson College's institutional review board. We attempted to contact all current and past *Partners* enrollees (N=261). Fifty-two (20%) had moved or died since their last contact with the program. Of the remainder, 86 (79 women; Median age = 58, Range = 36 to 77) completed QLACS and LET (41% response rate), either at reunion meetings (N= 46) or in mailed surveys (N= 40). Demographic and health data and open-ended comments about the *Partners* program were also collected. Program records provided participation indicators (attendance, services used, etc.). A minority (N=17) reported they are receiving cancer treatment now, with the remainder about equally divided between those in remission or cancer-free for at least five years.

Descriptive statistics were calculated and internal consistency reliability was examined for QLACS and LET. Correlations were computed with demographic and participation indicators.

Thematic analysis (Braun & Clark, 2006) was applied to free response data. Two observers read each participant's answers to our free response prompts (most memorable experience, useful concepts, lessons learned). They subsequently classified answers into thematic categories. After several rounds of discussion and reclassification, the coders agreed on three major themes, with further subthemes.

Results

Quality of Life (QLACS)

Figure 1 shows the profile of QLACS general domain scores, including negative and positive feelings, cognitive and sexual problems, pain, fatigue, and social avoidance. Internal consistencies (Cronbach alpha) for each domain score equaled or bettered those of samples in which QLACS was standardized (range = .73 to .93). The mean score for the Positive Feelings domain was much better than scores for 'problem' domains. Within subgroups of participants, those now in cancer treatment had the worst general domain scores.

Cancer domain mean scores ranged from 4.0 (Financial problems related to cancer) to 8.6 (Concern about cancer recurring); internal consistencies were between $\alpha = .81$ and $.93$. As above, individuals receiving cancer treatment scored worst on these scales.

Life Engagement (LET)

The mean LET score for *Partners* participants was 26.1 (SD=3.61), out a maximum of 30. LET internal consistency ($\alpha = .79$) was similar to published norms. Individuals with high LET scores had higher QLACS positive feelings scores ($r = .62$) and lower scores for negative feelings ($r = -.50$) and social avoidance ($r = -.38$).

Program-related Comments

Figure 2 shows the major themes and subcategories into which participants' comments were sorted, and how many participants' comments reflected an element of each theme. Subcategories with < 5 comments are omitted.

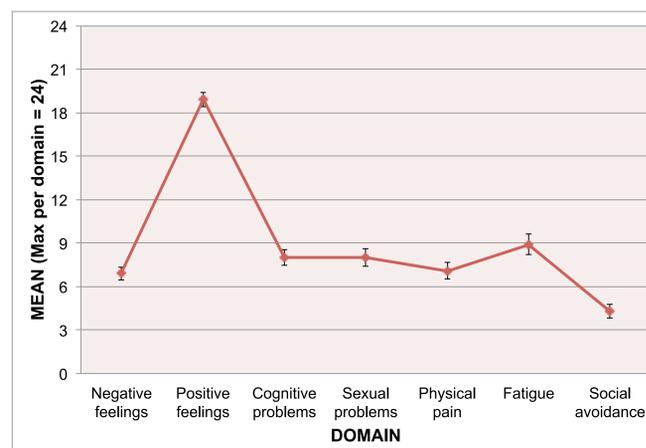


Figure 1: QLACS general domain scores (means +/- 1 std. err)

Social support	Skills & Techniques	Resilience & Well-being
<ul style="list-style-type: none"> • Mention of healers (n = 39) • Not alone, shared experience (n = 16) • Mention of other people (n = 15) • Talk, connect, gather with others (n = 12) • Healers care, understand (n = 11) <p>"The people in the class and the way Bonnie makes the class or session fit our needs!"</p>	<ul style="list-style-type: none"> • Yoga (n = 16) • Breathing techniques (n = 14) • Other techniques (e.g., laughing, meditation, journaling, expressing gratitude) (n = 12) • Exercise, being active frequently (n = 10) • Reiki (n = 6) <p>"I learned deep breathing and clearing my mind."</p>	<ul style="list-style-type: none"> • Relax, deal with stress, self-calming (n = 57) • Improved well-being (n = 15) • Strength, courage, fight (n = 11) • Focus, take care of self, awareness, self-love (n = 9) • Hope (n = 5) <p>"The program makes you realize how much inner strength [you have] when put into a tough situation."</p>

Figure 2: Comment categories and sample quotes

Conclusions

Standardized Measures

Participants had no difficulty completing QLACS and LET. Both measures produced internally consistent scores, and QLACS scales measuring participants' emotional states correlated in expected ways with LET. Individuals who are no longer receiving cancer treatment reported better QoL. If administered when individuals *begin* the program, QLACS and LET could be useful for evaluating program-related improvements, especially if scores of nonparticipants were also obtained at similar intervals.

Participants' Reflections on the Program

Participants were not directed to recall only positive experiences or state only positive lessons learned from the program, but their comments in about social support and resilience/well-being indicate they regard *Partners* as benefiting their overall quality of life. For example, the lessons they attributed to their *Partners* participation were uniformly positive and self-affirming. They also identified a wide variety of specific techniques they continue using.

Limitations

This study had no control group, so QoL effects of participating in complementary therapy offered by *Partners in Wellness* cannot be compared with that of cancer patients and survivors who have not gone through this treatment. Furthermore, variability among *Partners* participants, (e.g., age, type of cancer, cancer treatment modes) undoubtedly affected QoL. A previous study, for example, found that complementary therapy may have different effects, depending on participants' ages (Nguyen *et al.*, 2010). Our small sample makes controls for such variables impractical. Future studies, therefore, should be designed to facilitate comparisons and cause-effect conclusions.

Selected References

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