

Perceived social Support and Quality of Life among Clients Participating in

Cancer Support Services

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Abstract

Purpose: To collect and analyze participant demographic information and explore use of instruments to measure perceived social support and quality of life at a local cancer support program. Specific objectives included: 1) Gather and analyze participant demographic information and program utilization by participants for a non-profit cancer support agency, 2) Assess the extent to which those using the support programs experience perceived social support (PSS) and quality of life (QOL), and 3) Assess the utility of the survey process and selected instruments to guide program planning.

Background: Obtaining the diagnosis of cancer is traumatic, but support groups assist in emotional healing among group members. There is strong evidence correlating support group participation with PSS and QOL. The Wilson and Cleary model of QOL clearly links social support and QOL and provided the conceptual framework for this project.

Methods: A survey for self-reported participant demographics, support activities, QOL scores, and PSS scores was implemented. Both online and pencil and paper surveys were available. Instruments included Flanagan Quality of Life Scale (Cronbach's $\alpha = .82$ to $.92$) and the Multidimensional Scale of Perceived Social Support Scale (Cronbach's $\alpha = 0.91$) and a demographic survey created for this project.

Outcomes: All but one survey was completed online ($n=48$). Respondents were primarily white (44%), female, cancer free at the time of the survey, and over the age of 55. QOL and PSS scores within this sample emulated previous research of correlations between instruments and people with chronic illnesses.

Conclusion: Correlations of sample demographics and instrument scores reflected current literature; this project validates an effective and affordable means to evaluate program effectiveness. Future use of the survey is to better tailor services to meet the objectives of the agency to improve QOL for all individuals affected by cancer.

Keywords: Cancer, support group, quality of life, perceived social support

Cancer Support Survey

Chapter One

Cancer is an emotional rollercoaster for individuals diagnosed with the disease and their loved ones. Support groups are available through a number of community agencies including specialized cancer support agencies. These groups provide educational as well as, psychological and emotional support services. Cancer support groups give individuals the ability to transform negative events into healing opportunities through communication and social relationships. This chapter is an introduction to the project's background, problem, search strategy, evidence synthesis, and purpose.

Background and Significance

Diagnosis of cancer is a devastating event worldwide, even in developed countries. Experts predict about 40% of American's will be diagnosed with cancer at some point in their lifetime; with breast, prostate, and lung, each accounting for more than four thousand new cases yearly (NIH National Cancer Institute, 2015). Cancer is the second leading cause of death in the United States (US) and it is estimated there will be half a million deaths and 1.6 million new cases of cancer within the US by the end of 2015 (Siegel, Miller, & Jemal, 2015).

Cancer diagnosis used to be a notification of a life cut short but there is an increasing number of survivors living years to decades after diagnosis of cancer. Modern treatments have decreased the risk of dying from cancer by 22% between 1991 and 2011 (NIH National Cancer Institute, 2015). Decreasing the death rate and improving targeted treatments has increased survival rates in almost all cancers. From 1975 to 2010, five-year survival rate increased by 20% for all, but cervical cancer (NIH National Cancer Institute, 2015). Although there is no cure,

advances in health care have allowed cancer to be approached as a chronic disease as more people.

Chronic diseases not only require physical, mental, and emotional adjustments for the individual diagnosed with the disease, but families and significant others are also significantly impacted. Caregiver burden, depression, and stress increased as well as decreased social functioning, physical health, and QOL (Stamataki et al., 2014). Regardless of length of life after diagnosis, millions of cancer patients and their families go through emotional turmoil when facing life altering, poor prognosis. There are multiple methods to cope with the stress of a cancer diagnosis for cancer patients and their family members; the use of social support is a common intervention.

Perceived Social Support

The American Psychological Association defines social support as a structural format, such as resources, material aid, social integration, and informational aid that others provide to help a person cope with stress (APA, 2015). Perceived social support (PSS) is the subjective interpretation to the relationship transaction between individuals (Zimet, Dahlem, Zimet, & Farley, 1988). Functional components of social support comprise transactions between individuals in the acts of sharing, reciprocating, and advising within a network that improves psychological well-being and physical health (Reblin & Uchino, 2008).

Social support groups increase PSS and an increase in individual QOL. Experiencing low levels of perceived social support (PSS) increased the risk of deteriorating health. Social support has been found to have an inverse relationship with inflammatory processes. Social disconnectedness has been associated with higher levels of chronic stress, systematic inflammation, and cancer progression (Goyal, Terry, Jin, & Siegel, 2014; Hughes et al., 2014;

Swede et al., 2014; Yang, LI, & Frenk, 2014).). . Lack of PSS increases the risk of illness and death. In a recent meta-analysis, researchers reported a 25-30% increase in mortality associated with social isolation, loneliness, and living alone (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015).

Quality of Life

As the population of long-term cancer survivors grows, addressing QOL and its effect on overall health has become increasingly important. Quality of life is a multi-dimensional concept with domains related to physical, mental, emotional, and social functioning and is one of Healthy People 2020 four overarching goals (Centers for Disease Control and Prevention [CDC], 2013). Quality of life (QOL) measures subjective evaluation of personal experiences, health states, and perceptions in forming personal life expectations (Burckhardt & Anderson, 2003). Increased QOL has been found to precipitate disease resistance, resilience, and self-management through protective characteristics and conditions that foster health (Healthy People 2020, 2015). Although multiple studies link the value of QOL to individual characteristics, social connections, health status, and perceptions, the accuracy of the predictions remains in question.

Quality of life and Perceived Social Support

Positive correlations between QOL and use of PSS are well documented. When participating in support groups, interactions and relationship bonding augments members' perception and outlook on life (Applebaum et al., 2014; Brand, Barry, & Gallagher, 2014; Matthews, Tejada, Johnson, Berbaum, & Manfredi, 2012). Multiple researchers identifying relationships between social support and health also find quality, or perception of received social support, to be better predictors of emotional health than number of support entities (Ozbay et al., 2007; Penedo et al., 2012; Roohafza et al., 2014).

Support groups commonly used as a means of providing social support. They generally offer emotional and educational support and provide a safe place to discuss difficult issues. Support groups gather people with similar life situations to communicate advice, comfort and encouragement for one another through social relationships and interpersonal transactions (Breastcancer.org, 2015; Glanz, Rimer, & Viswanath, 2008; Oxford Dictionaries, 2015). Cancer support groups usually differentiate by diagnosis or focus, such as age, race, or location. Available online, face to face, or by telephone, support groups improve QOL for participants within various cultures (Bouma et al., 2015; Huang & Hsu, 2013; Sammarco & Konecny, 2010). Most support groups are free to participants, with financing supported by donations and charity.

Previous studies have found consistent trends of individual characteristic that correlate with PSS and QOL. Studies have found that support group participants are primarily middle-aged, well-educated, middle class females (Grande, Myers, & Sutton, 2005; Im et al., 2007; Sautier, Mehnert, Höcker, & Schilling, 2014).

Project Site and Internal Evidence

There are many support resources for Arizona residents including the American Cancer Society, Cancer Support Community, and Cancer.Net, which provide in-person or online delivery methods. A cancer support agency, with its main campus located in downtown Phoenix, Arizona, provided the site for this project. The stated mission of the organization is to ensure all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. This agency serves family, friends, caregivers, and people with any stage of cancer. Services include support groups, education, social connections, healthy lifestyle activities, and resources. All programs are evidence-based, led by professionals, and are at no cost to the participants. This 501(c)3 non-profit organization and services are financially provided by

individual and corporate contributions. There is one full time employee, the Program Director, with all other positions being part-time or volunteer. This agency requested assistance to collect information related to its participants including: demographic information and impact of support services programming on participants.

PICOT

This inquiry lead to the clinical relevant PICOT question, “does the use of social support services, compared to not using social support, affect perceived social support and quality of life for patients with cancer and/or their caregivers?”

Search Strategy

Research relevant to the PICOT question was searched within Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed (Medline), PsycINFO (ProQuest), and the Cochrane Library (Appendices A-D). A mix of fourteen published studies and systematic reviews were collected for this review.

CINAHL (EbscoHOST) outcomes were best reached with the use of Boolean/Phrase. Beginning search terms were *support service*, *social support*, and *quality of life*, which resulted in 2,174 results, as seen in appendix A. The search performed used the following addition search terms: *cancer*, *oncology* to in retrieving 464 peer-reviewed articles. Narrowing the time frame to cover the last five years, January 2010 through July 2015, in US adult population, and written in English produced 70 peer-reviewed articles that allowed abstract review. Within the final fourteen articles, this database search yielded six of those articles.

PubMed (Medline) search began with the use of various search term truncations of MeSH Major topics, MeSH terms, and Pubmed’s “Other terms” for the following words: *social*

services, social support, quality of life, produced 78,936 results. Additional terms, such as *oncology, cancer, quality life index* reduced the list to 822 articles; see appendix B. Limiting the time parameters of publishing within the last five years and written in English with adult populations, decreased the list to 18 abstracts for review. Of the fourteen articles, four new articles were retrieved from this database. Four articles were recurring articles from the CINAHL search collection.

Within PsycINFO, 33,360 journal articles were retrieved using the following search terms: *social support, social service, and social group*. Incorporating *oncology, cancer, quality of life, well being, peer support, adult outpatient in the US* with the first terms, resulted in a reduction to 21,660 articles for review. Limitations of time, format, and language: 2010-present, peer reviewed journal articles, and English; decreased results to a manageable 37 articles, see Appendix C. This search found one of the final fourteen papers appraised within this review.

The electronic search of the Cochrane Library yielded 9,809 publications when *social support, social services, support group, and perceived social support* were searched (see appendix D). When *oncology, cancer, quality of life, and psychosocial* terms were added to the search, 287 studies were collected. Eliminating the terms *psychological, HIV, exercise, and diabetes* reduced the search to 36 articles. Limitations to the time range (January 2010 thru July 2015) and gave the final 23 abstracts to review. None of the final articles came from this database. One of the final articles came from an ancestral search of several articles within this database, which is discussed later in this paper.

Ancestral hand search was conducted due to a reduced number of articles specific to the terminology of PSS and QOL. While searching, most of cancer support programs were well studied in the 1990's and early 2000's. Recent articles involved other diseases, psychotherapy,

and various medical systems that do not translate to useful evidence for participants of this cancer support agency. Ancestry search was conducted on nine articles found in the databases and the articles with related topics. One article was found for final reviewing as a result of this search technique. Flowchart of this process is found in Appendix E Figure 1.

Evidence Synthesis

For this review, 13 studies and one literature review highlight the characteristics to affecting QOL through social support (Appendix F, Table 1). Of the 14 studies, most are observational studies with low levels of evidence; level III on the National Health and Medical Research Council (NHMRC) evidence hierarchy (NHMRC, 2009). Due to the qualitative nature and number of possible factors impacting PSS and QOL, high risk of bias were necessary to filter out possible characteristics that influence QOL in participants of cancer support services. The use of chi-square and the independent t-test demonstrated demographics of the intervention groups and control groups were not significantly different in any of the studies (Appendix F, Table 1).

Valid and reliable evaluation tools were used in 11 studies. Although various tools were used, FACT and medical outcome study short form health survey were used to evaluate QOL of these eleven studies (Appendix F, Table 1). Heterogeneity of methodology, intervention, tools, and participants did not allow for pooling of results. Correlation and multivariate regression models were used to find characteristics that correlated to QOL or PSS statistically.

Between all the collected studies, homogeneity is the positive correlation PSS has on QOL in people affected by cancer (Appendix G, G2). The systematic review performed a descriptive analysis of eleven studies with the same conclusion with the addition of coping as a mediating factor, which is consistent with the results reported by Paterson et al (2013) and Zhou

et al. (2010). Despite the evidence of benefits, the use of support groups was reported to be a small percentage of the cancer-affected population in several studies (Leow, Chan, & Chan, 2014; Morse, Gralla, Petersen, & Rosen, 2014). Another repeating report was the main supply of social support for survey participants was by spouses and family, more than any other source (Leow et al., 2014; Leung, Pachana, & McLaughlin, 2014; Salonen, Rantanen, Kellokumpu-Lehtinen, Huhtala, & Kaunonen, 2014; Sammarco & Konecny, 2010).

Evidence review through critical appraisal and synthesis found individual characteristics that may predict low levels of QOL or PSS. Due to the large degree of heterogeneity between studies, each demographic category suspected to affect QOL or PSS was collected in table 2 for synthesis (Appendix I). To be included into table 2, the characteristic had to be identified by two or more studies to validate correlations on QOL. Regardless of direction, characteristics that were reported to have a correlation with QOL were independently included. Studies that collected the information about individual characteristics but did not calculate correlations were also included (Appendix I, Table 2). Characteristics found to be relevant to QOL were calculated by dividing the number studies that reported correlating factor to the total number of studies that addressed that independent factor. Once placed on the table, differences between caregivers and patients emerged.

Due to the large degree of heterogeneity and limiting number among the review studies, some characteristics are unable to confirm their importance in affecting QOL. Characteristics, such as, occupation, religion, optimism, cancer stage, and insurance had no clear relation to QOL although, this may be due to a large degree of heterogeneity among studies and limited number of studies. Marriage, cancer type, and cancer treatment type did not seem to affect QOL in either population. Race and length of time with cancer diagnosis correlate more strongly with

caregivers' than with patients' QOL. Isolating only the studies that surveyed cancer patients, several characteristics were identified to affect QOL. In the specific populations, income, employment, age, gender, education, depression status, and comorbidities have a correlation on patient QOL and PSS. Some studies focused exclusively on gender specific populations and others reported caregivers were mainly female, leaving gender and cancer types as characteristics that might have been skewed in this review. The results of this review compile the necessary information needed for a cancer support survey to establish characteristics influencing participant QOL and identifying areas for improvement.

Purpose Statement

There are three specific aims of this project: 1) To gather and analyze demographic information and program utilization by participants 2) To assess the extent to which perceived social support and QOL correlates with programs designed to increase social support, and 3) To pilot the survey process, questions, and instruments for future impact studies.

Chapter 2

This chapter will discuss the conceptual framework and how it guided the project. Project methods, statistical analysis, and results will also be included. Discussion covers summary of result interpretations and links to previous literature.

Conceptual framework

The Health-Related Quality of Life Model (Wilson & Cleary, 1995) was used to guide this project (Figure 1). The model depicts the relationships among these variables that affect QOL. The theory is based on viewing health as a continuum of biological, social, and psychological complexities that are dominant causal associations (Wilson & Cleary, 1995). The model illustrates the impact of individual and environmental characteristics that link conceptually specific measures to a person's QOL. Although individual characteristics may not be modifiable, the environment and symptom management allow room for interventions.

In a study to determine impediments most associated with QOL in people with advanced cancer, Rodriguez and associates (2013) found that among 65 variables, the most significant predictor of QOL was social support. Perceptions of general health and energy followed. Social support is a modifiable environmental characteristic that has demonstrated potential to improve QOL and PSS in those affected by cancer.

Evidence Based Practice Model

The Iowa model of evidence-based practice (EBP) model delineates the procedures to successfully execute organizational changes utilizing evidence. Outlined in Figure 2, the Iowa model, designed by the University of Iowa Hospitals and Clinics (2015) describes seven steps to introduce, develop, and evaluate evidence-based practice. Permission to use this model in written material was obtained from the University of Iowa Hospitals and Clinics. Within the Iowa

model, the first step is to use problem or knowledge-focused triggers as catalyst for process improvement that encompass clinical and operational systems of an organization through research findings (Titler et al., 2001). The model outlines a process of decision points in evaluating sufficient research, feedback loops and the process to conduct own research (Titler et al., 2001; Titler & Moore, 2010). With the absence of internal data, the survey serves to collect the internal benchmark data for this organization (Figure 2, problem-focused triggers, #3). It is imperative to complete the benchmark data in order to proceed with future interventions.

Project Methods

Ethics

This project was approved by the Arizona State University Institutional Review Board. Site authorization was also obtained from the organization.

Setting

The setting for this project was a non-profit cancer support agency cancer support agency located in the Phoenix metropolitan area. The agency offers services in a homelike setting that is informal, welcoming, and hospitable. There are multiple services available to any person affected by cancer, regardless of type, stage, or relationship to the diagnosed. The organization offers support services, healthy lifestyle activities, educational seminars, social connections, and resources. Services are evidence based, professionally facilitated, and are no cost to participants. There are online, in-person, and subsidiary programs to fit the needs of those participating. Eight hundred members that attended the 1,074 program sessions available in 2015.

Participants

Participants were 18 years of age and older adults participating in the services offered by this cancer support agency. This includes people with cancer, caregivers, friends, and family of

people with cancer. Responses from minors, those unable to read or understand English, and anyone not using the services offered by this cancer support agency within the last year were excluded.

Procedure

To assess characteristics of individuals participating in programs and the number and types of programs being utilized by participants, the student project leader created a survey. The survey was used to collect self-reported participant demographics and participation in cancer support activities. The survey was available online or on paper from January 28, 2016 through March 8, 2016. Online surveys were emailed to participants through the organization's e-Blast, delivering the online survey link to 4,000 emails. The email had a cover letter with a link to the SurveyMoz survey. Paper surveys had a printed cover letter and were available only at the main campus (downtown, Phoenix, AZ) during open administration hours (Monday through Friday, 9am-5pm). Card-sized flyers were publicly displayed on tables of the main campus. Program leaders, class instructors, and volunteers verbally informed the availability of the surveys.

Surveys were expected to take approximately 30 minutes to complete the demographic survey and measures of PSS and QOL. Using SurveyMoz premium plan, responses were anonymous, saved on a secure server and downloaded directly into SPSS. For paper survey responses, a designated locked ballot box (metal) was available for completed surveys. The student project leader entered raw data into the SPSS manually for paper surveys.

To encourage participation, the agency gave a five-dollar restaurant coupon from a local restaurant to all individuals completing the survey. The coupons were donated to the organization as 500 five-dollar paper coupons from the restaurant prior to the planning of this project. A thank you page appear at the end of the online survey, which participants presented to

main campus volunteers to receive the coupon. The thank you page was not recorded, saved, or linked to any response. For paper surveys, the thank you page was the last page of the survey. Once completed and participants inserted paper surveys into the locked ballot box, the participant was given a coupon by agency volunteer staff.

Outcomes measures

Participant activity, demographics, QOL, and PSS were measured. The Multidimensional Scale of Perceived Social Support (MSPSS) is a 12-item self reported, time effective scale that distinguishes PSS from three strong factorial sources: significant other; family and friends. Internal reliability by Cronbach's coefficient alpha is .91, with significant other, family, and friends' alphas .90, .94, and .95, respectively (Dahlem, Zimet, & Walker, 1991). The scale performs adequate stability at retesting 2 to 3 months later, with $r = .72$ to $.85$ (Zimet, Dahlem, Zimet, & Farley, 1988).

The Flanagan Quality of Life Scale (QOLS) is a 16-item questionnaire that measures health-related quality of life. Construct validity assessments of the scale showed high internally consistent ($\alpha = .82$ to $.92$) and high test-retest reliability over three weeks in stable chronic illness groups, $r = 0.78$ to $r = 0.84$ (Burckhardt & Anderson, 2003). The scale has a fairly stable factor structure across diverse adult samples in health, culture, and gender.

Both scales were selected due to consistent demonstration of strong reliability and validity among diverse populations. Various populations, such as cancer patients, chronic diseases, caregivers, greater than 11 years of age, and multiple countries used these scales. Unlike other scales, these questionnaires are used within healthy and ill populations without need to change to another format or version. Both questionnaires are public domain, do not require

formal permission, and are free of charge (Burckhardt, Anderson, Archenholtz, & Hägg, 2003; Multidimensional Scale of Perceived Social Support (MSPSS), n.d.).

Data collection and analysis plan

Data collection was conducted January 28, 2016 to March 8, 2016. SurveyMoz transferred raw data to Excel files for data cleaning and instrument scoring calculations. The QOLS scores, ranging from 16-112, were totaled with the higher scores indicating higher quality of life. Missing data was replaced with entering the mean score for the missing items as instructed for scoring the QOLS. The MPSS was segmented into subscales for identifying specific areas that lack support and the scale used the grand total for overall scale of PSS. Significant other subscale summed the items 1, 2, 5, & 10, and then divided by 4. The family subscale, items 3, 4, 8, & 11 summed, and then divided by 4. Friends' subscale summed the items 6, 7, 9, & 12, and then divided by 4. Total Scale added across all 12 items, then divided by 12. Descriptive and frequency statistics were performed for demographics. The excel file merged into SPSS (v23) to perform Spearman and Pearson correlations. Statistical tests were executed with a statistical probability of 95% confidence interval ($p < 0.05$).

Project Results

A total of 71 (57%) surveys were returned; final sample size for analysis was 48 surveys after eliminating those that did not fit the inclusion criteria. Most people who responded to the survey were people diagnosed with cancer (87.2%; $n=41$) and currently cancer free (43.6%; $n=17$). Respondents were mainly white (93.5%; $n=43$), retired (43.8%; $n=21$), female (76.6%; $n=36$), and 70.8% ($n=34$) were 55 years of age and older. See Appendix K, table 3 and table 4 for a complete description of the sample. A chi-square goodness fit test was completed to compare several demographic frequencies (type of respondent, age ranges, gender, race,

ethnicity, and cancer type) to characteristics of participants in earlier local and national agency surveys. Based on earlier findings, this survey sample appears to be comparable and an accurate representation of this agency's population with the exception of the distribution of participants that identify as Hispanic. The proportion of Hispanic participants in this study exceeded the survey results from the local cancer support group and was lower than the proportion of Hispanic participants in the national survey. Significant deviation from these hypotheses was found at the local level ($\chi^2(1) = 4.67, p = .031$) and on the national levels ($\chi^2(1) = 6.48, p = .011$). The 11% of respondents within this project were Hispanic, in between the expected local and national values. No other significant deviations from the hypothesized values were found.

All but one of the 71 responses were completed online, 57% of responses were the day of the E-blast announcement. One survey was filled out on paper and manually entered. The survey took an average of 11 minutes for respondents to complete, with most completing in seven minutes.

Descriptive statistics on the QOL score and MSPSS scores are provided in table 5 in Appendix K. QOL scores ranged from 56-102 with a mean 84 (SD 12.2). The average score was consistent with other chronic illness groups, such as systemic lupus erythematosus, rheumatoid arthritis, and chronic obstructive pulmonary disease (Burckhardt & Anderson, 2003). This survey sample appeared to be a fair reputation of cancer effected populations.

Multiple Spearman's rho correlation coefficients and chi-square tests of independents was calculated for relationships between all variables and a.) QOL total score; b.) MSPSS overall score; c.) MSPSS significant other subscale score; d.) MSPSS family subscale score; and e.) MSPSS friend subscale score; according to appropriate levels of measurement. Refer to Appendix K, table 6 for coefficient values. The following variables were found not to have

significant correlations with the instruments: age, ethnicity, living alone, veteran status, relationship status, race, working status, education, types of cancer, months of having cancer, reoccurrence of cancer, months participating in the agency's programs, and personal diagnosis of cancer. In this population, these variables appear to be independent characteristics.

A Spearman rho correlation coefficient was calculated for the relationship between participant's QOL total score and their MSPSS scores (overall score and subscales for significant other, family, and friends). A statistically significant positive correlation was found between QOL and all MPSS overall score ($r(34) = .458, p < .005$) see table 6. This indicated a significant relationship between PSS and QOL; participants who perceive higher social support tend to have higher QOL.

A stronger relationship was noted between the MSPSS subscale scores. A Spearman rho correlation coefficient calculated a statistically significant, very strong correlation found between MSPSS overall score and MSPSS family subscale score ($r(34) = .890, p < .001$). The strong relationship similar replicates the results supporting validity and reliability of the MSPSS instrument (Dahlem et al., 1991; Zimet et al., 1988). This survey resulted in supporting another established MSPSS's correlation between friend subscale and gender. A chi-square test of independence was calculated comparing the scoring differences in men and women. A significant interaction was found ($\chi^2(1) = 24.56, p = .026$), along with, differences in female mean score 5.6 (SD .199) and male mean scores at 4.86 (SD .442). Similar to results found by Osman and associates (2014), these divergences demonstrated internal variance among gender bias within the friends subscale.

A spearman's rho correlation coefficient was calculated for the relationship between age ranges and attending different type of healthy lifestyle events. A moderate correlation was (r

(46)= .306, $p=.034$). Increase in age was associated to attending more different types of healthy lifestyle events.

A spearman's rho correlation coefficient was calculated for the relationship between program frequency and the amount of time going to the agency. A moderately negative correlation was found to be significant ($r(26) = -.407, p=.032$). A decrease in program attendance frequency as time passes.

No significant relationships were found between the instruments and program frequency or number of different programs. Appendix K, table 7. These results are consistent with the Ozbay and associates (2007), findings and concluded the number of different support programs or the frequency of attendance did not influence the perception of social support.

Empowerment was an important value stated within the project site's mission. At the request from the project site, perceived health control was measured and correlated to various scores and activity participation. The question within the survey asked, "To what extent do you feel you are in control with your health care? 0 (not at all) – 5 (complete control)." A spearman's rho correlation coefficient showed a statistically significant weak correlations between perceived health control and 1) MSPSS overall, 2) friend, and 3) family scores, 4) the attendance to different lifestyle programs and 5) frequency of attendance to healthy lifestyle activities. Refer to table 8 for individual spearman's rho correlation coefficients. The significant showed the perception of health control was positively related to overall PSS, family and friend PSS and healthy lifestyle activities.

Discussion

The correlations between QOLS, MSPSS overall score and MPSS subscales scores were similar to the current literature. Consistent with previous support group studies, other authors

concluded positive correlation existed between PSS and QOL in people affected by cancer (Rodriguez, Mayo, & Gagnon, 2013; Paterson, Jones, Rattray, & Lauder, 2013; Zhou et al., 2010). A stronger relationship was noted among the MSPSS scores, which replicated the results that supported validity and reliability of the MSPSS instrument (Dahlem et al., 1991; Zimet et al., 1988). Additionally, this survey's outcomes supported another established MSPSS's correlation between male and female scores under the friend subscale. Osman and associates (2014) found these divergences between the sexes demonstrated internal variance among gender bias within the friends subscale. The authors' deduced genders view the importance of PSS received from friends differently in which women weight friend social support perception more heavily than men. Between program activity and PSS scores, no significant correlations were found within this surveyed population; validated the number of support sources did not influence PSS. With the sample representing similar demographics and responses emulating previous research, this survey process and instruments are acceptable means to evaluate PSS and QOL of participants using cancer support programs.

Conclusion

This project gathered baseline data about a cancer support agency's participants through a survey format, piloting a survey process and instruments to measure PSS and QOL. Program participants' demographics reflected previously surveyed local and national populations. Instrument scores and correlations were consistent with previous literature, substantiating theories, such as the number of support does not affect PSS, and people with high PSS tend to have high QOL. The average survey time to complete was two thirds less than predicted. Online survey reached thousands through email and was the preferred method to completing the survey. At \$115 this process of evaluations was a reasonable expense for the agency.

Chapter 3

Intro

The current and potential impacts this project brought to the support agency are justified by the financial implications it took to perform a pilot survey. In coordinating this project, reflection of student leader barriers are discussed. Project sustainability was solidified with future studies with this agency and ASU. As with any implementation, there were gaps in knowledge and reported limitations within this project.

Impact

While this cross-sectional study does not distinguish causes contributing to QOL or PSS directional effects, piloting the survey process, questions, and statistics may contribute to this organizations ability to better evaluate and tailor programs to enhance PSS and QOL. Such results may contribute to better reporting of program impact. Reporting impact study outcomes increases donor contributions and elevates the agency's reputation (America's Charities, 2014).

Project Costs and Sustainability

Printing cost at a local Aphagraphics for 100 reminder cards and 30 consent, survey, and instrument packets was \$80. The lockbox cost \$35 from Amazon. At the cost of \$115 and a few hours of set up time, this project is reasonably obtainable for most non-profit organization. Once established, the cost to repeating the survey is needed only for printing cost and advertising the survey.

Conclusion

This project gathered baseline data about cancer support agency's participants through an online survey format in preparation for following studies to bring clarity of the impact the

agency's social support programs have on participants. Further work is needed to correlate cancer support program utilization, the QOLS and the MSPSS scores to ensure quality programs that maintain the agency's mission, "So that no one faces cancer alone."

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Appendix A



Searching: CINAHL Plus with Full Text | [Choose Databases](#)

Suggest Subject Terms

Select a Field (option... ▼ ?
 AND ▼ Select a Field (option... ▼
 AND ▼ Select a Field (option... ▼

[Basic Search](#) | [Advanced Search](#) | [Search History](#) ▼



Search History/Alerts

[Print Search History](#) | [Retrieve Searches](#) | [Retrieve Alerts](#) | [Save Searches / Alerts](#)

<input type="checkbox"/> Select / deselect all		<input type="button" value="Search with AND"/>	<input type="button" value="Search with OR"/>	<input type="button" value="Delete Searches"/>	<input type="button" value="Refresh Search Results"/>
Search ID#	Search Terms	Search Options	Actions		
<input type="checkbox"/> S10	S3 AND S4	Limiters - Published Date: 20100101-20151231 Narrow by SubjectGeographic: - usa Narrow by Language: - english Narrow by SubjectAge: - all adult Search modes - Boolean/Phrase	View Results (70) View Details Edit		
<input type="checkbox"/> S9	S3 AND S4	Limiters - Published Date: 20100101-20151231 Narrow by Language: - english Narrow by SubjectAge: - all adult Search modes - Boolean/Phrase	View Results (140) View Details Edit		
<input type="checkbox"/> S9	S3 AND S4	Narrow by SubjectAge: - all adult Search modes - Boolean/Phrase	View Results (140) View Details Edit		
<input type="checkbox"/> S8	S3 AND S4	Limiters - Published Date: 20050101-20151231 Narrow by Language: - english Narrow by SubjectAge: - all adult Search modes - Boolean/Phrase	View Results (227) View Details Edit		
<input type="checkbox"/> S7	S3 AND S4	Limiters - Published Date: 20050101-20151231 Narrow by SubjectAge: - all adult Search modes - Boolean/Phrase	View Results (228) View Details Edit		
<input type="checkbox"/> S6	S3 AND S4	Limiters - Published Date: 20050101-20151231 Search modes - Boolean/Phrase	View Results (352) View Details Edit		
<input type="checkbox"/> S5	S3 AND S4	Search modes - Boolean/Phrase	View Results (464) View Details Edit		
<input type="checkbox"/> S4	S1 AND S2	Search modes - Boolean/Phrase	View Results (2,174) View Details Edit		
<input type="checkbox"/> S3	oncology OR cancer	Search modes - Boolean/Phrase	View Results (214,936) View Details Edit		
<input type="checkbox"/> S2	quality of life	Search modes - Boolean/Phrase	View Results (90,518) View Details Edit		
<input type="checkbox"/> S1	support service* OR social support	Search modes - Boolean/Phrase	View Results (21,124) View Details Edit		




Appendix B

History


[Download history](#) [Clear history](#)

Search	Add to builder	Query	Items found	Time
#5	Add	Search (((("oncology"[Other Term]) OR "cancer"[Other Term])) AND (((("support services"[Other Term]) OR "social support"[MeSH Major Topic]) AND ("quality of life"[MeSH Major Topic] OR quality of life index)))	21	15:38:52
#9	Add	Search (((("oncology"[Other Term]) OR "cancer"[Other Term])) AND (((("support services"[Other Term]) OR "social support"[MeSH Major Topic]) AND ("quality of life"[MeSH Major Topic] OR quality of life index))) Filters: published in the last 5 years; English; Adult: 19+ years	18	15:33:03
#8	Add	Search (((("oncology"[Other Term]) OR "cancer"[Other Term])) AND (((("support services"[Other Term]) OR "social support"[MeSH Major Topic]) AND ("quality of life"[MeSH Major Topic] OR quality of life index))) Filters: published in the last 5 years; English	20	15:29:41
#7	Add	Search (((("oncology"[Other Term]) OR "cancer"[Other Term])) AND (((("support services"[Other Term]) OR "social support"[MeSH Major Topic]) AND ("quality of life"[MeSH Major Topic] OR quality of life index))) Filters: published in the last 5 years	21	15:29:08
#6	Add	Search (((("oncology"[Other Term]) OR "cancer"[Other Term])) AND (((("support services"[Other Term]) OR "social support"[MeSH Major Topic]) AND ("quality of life"[MeSH Major Topic] OR quality of life index))) Filters: published in the last 10 years	21	15:29:04
#4	Add	Search (((("support services"[Other Term]) OR "social support"[MeSH Major Topic]) AND ("quality of life"[MeSH Major Topic] OR quality of life index))	822	15:28:49
#3	Add	Search ("oncology"[Other Term]) OR "cancer"[Other Term]	69212	15:28:38
#2	Add	Search ("quality of life"[MeSH Major Topic] OR quality of life index	78936	15:26:19
#1	Add	Search ("support services"[Other Term]) OR "social support"[MeSH Major Topic]	19019	15:18:43


Appendix C


ProQuest   

All databases > Social Sciences databases > PsycINFO

PsycINFO  AMERICAN PSYCHOLOGICAL ASSOCIATION

Basic Search | Advanced Search | About


(mjsub(social support) OR su((support group OR support service))) AND su((oncology OR cancer)) AND su((quality of life OR well being)) AND su(Peer support) AND outpatient AND lo(US) 

Peer reviewed  [Modify search](#) [Tips](#) [Save search/alert](#)

Additional limits - Date: After January 01 2010; Record type: Peer-reviewed Journal; ... [Show all](#)

Related searches There are

37 Results [Search with](#)

Relevance 

Narrow results by

- Peer reviewed
- Source type
- Scholarly Journals (37)

Additional limits

Date: After January 01 2010

Record type
Peer-reviewed Journal

Language
English

Age group
Adulthood (18 Yrs & Older)

Population
Outpatient


[Show all additional limits](#)



[Cite](#) [Email](#) [Print](#) [More](#)

[Brief view](#) | [Detailed view](#)

tal health outcomes in patients with advanced cancer. [Preview](#)

ord-Bessen, Jennifer; Pessin, Hayley; Rosenfeld, Barry; et al. **Psycho-Oncology**

ext 

  Internet peer support for individuals with psychiatric disabilities: A randomized controlled trial. [Preview](#)

Appendix D



Trusted evidence.
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Search	Search Manager	Medical Terms (MeSH)	Browse
To search an exact word(s) use quotation marks, e.g. "hospital" finds hospital; hospital (no quotation marks) finds hospital and hospitals; pay finds paid, pays, paying, payed)			
Add to top			View fewer lines
<input type="checkbox"/>	<input type="button" value="Edit"/>	<input type="checkbox"/>	<input type="button" value="9809"/>
#1	"social support" or social services or "support group" or "perceived social support"		
<input type="checkbox"/>	<input type="button" value="Edit"/>	<input type="checkbox"/>	<input type="button" value="99888"/>
#2	oncology or cancer		
<input type="checkbox"/>	<input type="button" value="Edit"/>	<input type="checkbox"/>	<input type="button" value="44512"/>
#3	"quality of life"		
<input type="checkbox"/>	<input type="button" value="Edit"/>	<input type="checkbox"/>	<input type="button" value="7489"/>
#4	psychosocial		
<input type="checkbox"/>	<input type="button" value="Edit"/>	<input type="checkbox"/>	<input type="button" value="278"/>
#5	#1 and #2 and #3 and #4 in Cochrane Reviews (Reviews only) and Trials (Word variations have been searched)		
<input type="checkbox"/>	<input type="button" value="Edit"/>	<input type="checkbox"/>	<input type="button" value="60"/>
#6	#5 not psychological		
<input type="checkbox"/>	<input type="button" value="Edit"/>	<input type="checkbox"/>	<input type="button" value="58"/>
#7	#6 not HIV		
<input type="checkbox"/>	<input type="button" value="Edit"/>	<input type="checkbox"/>	<input type="button" value="39"/>
#8	#7 not exercise		
<input type="checkbox"/>	<input type="button" value="Edit"/>	<input type="checkbox"/>	<input type="button" value="36"/>
#9	#8 not diabetes		
<input type="checkbox"/>	<input type="button" value="Edit"/>	<input type="checkbox"/>	<input type="button" value="23"/>
#10	#9 Publication Year from 2010 to 2015		
<input type="button" value="Clear Strategy"/>		Search Help	
<input type="button" value="Save strategy"/>		<input type="checkbox"/> Highlight orphan lines	

Appendix E Figure 1. Study flow diagram

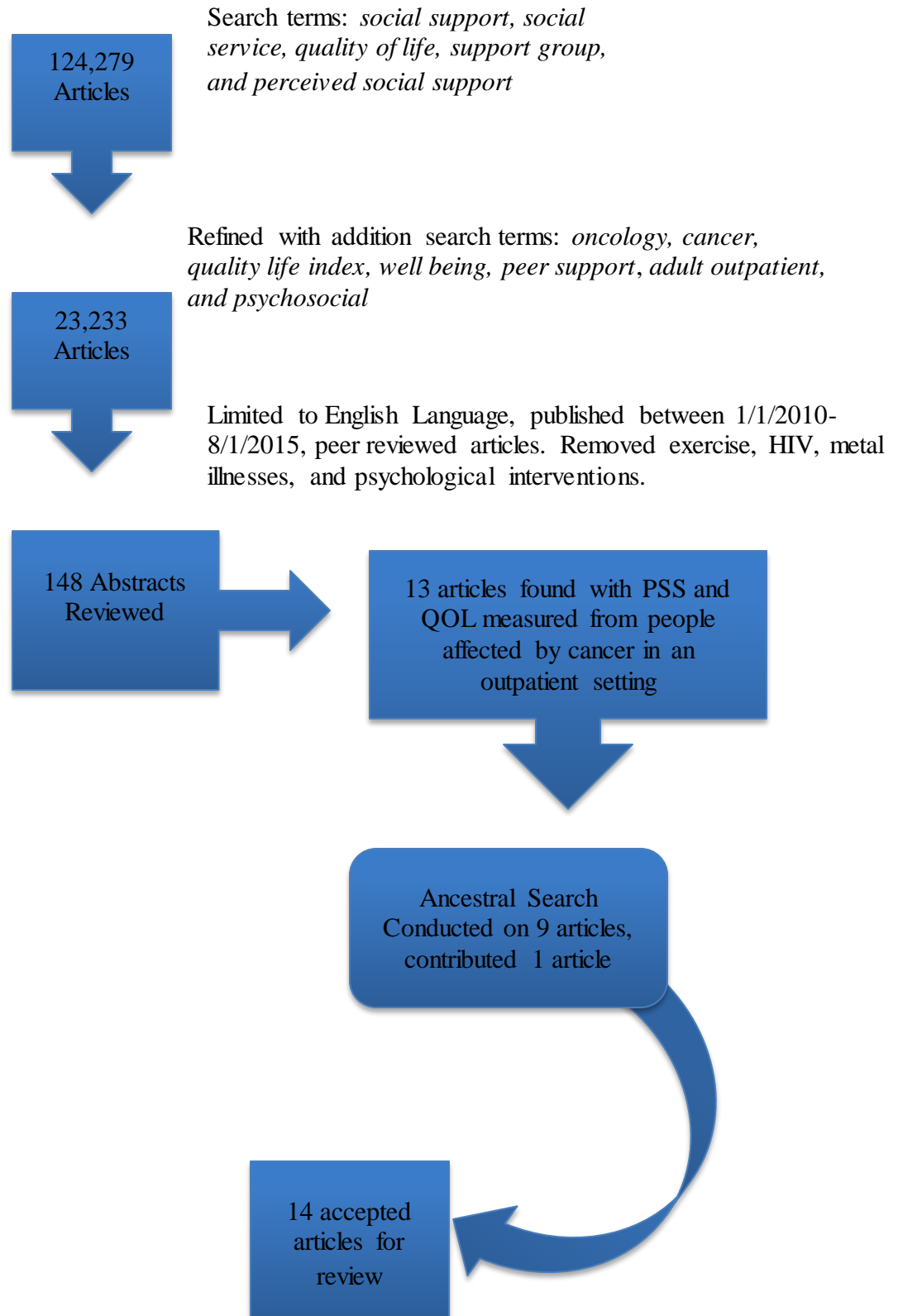


Table 1

Appendix F Evaluation Tables

Citation	Conceptual Framework	Design / Methods	Sample / Setting	Major Variables	Measurement	Data analysis	Findings	Practice application
(Brand, Barry, & Gallagher, 2014) Social support mediates the association between benefit finding and quality of life in caregivers Country: Ireland Funding: None Bias: Non-response 16%	Social support mediates benefit finding to QOL	Cross-sectional survey Measurement-of-mediation design Purpose: Examine the positive psychosocial predictors and indirect effects between benefit finding and QOL in CG Recruited: word of mouth and CG support groups	n: 84 CG Mainly white, female, married IC: Not disclosed, but assumed CG of mental and physical difficulties EC: not disclosed Attrition: One time 92-question survey available 3-month period. Dates not given 84% response rate	IV1: socio-demographics DV1: QOL DV2: SS DV3: benefit finding DV4: optimism	AC-QoL questionnaire ($\alpha = .93$) 19-item Medical Outcome Study Social Support Scale ($\alpha = .96$) Stress-Related Growth Scale ($\alpha = .94$) test-retest reliability ($r = .95$) Life Orientation Test-Revised ($r = .79$) ($\alpha = .78$)	Used SPSS Bivariate correlation analyses Indirect effects analysis Bootstrap procedure Independent t-test	NS attending support group and those not attend Benefit finding (IV) → social support (Mediator) → QOL (DV) ($b = .90, t (84) = 3.39, p < .001$). Optimism (Mediator) → benefit finding = NS QoL → social support → benefit = NS	LOE= III-3 Strengths- positive affect of benefit finding and PSS on CG QOL Weaknesses- changed Life Orientation test weakening validity, n was from support groups and various CG types Conclusion- benefit finding ↑ the effect on CG PSS, thus ↑ QOL Application- There is a relationship b/w SS and QOL

AA: African American; avg: average; b/w: between; BL: baseline; BrCA: breast cancer; CA: cancer; CG: caregiver; DS: depressive symptoms; DV: dependent variables; dx: diagnosed; EC: exclusion criteria; edu: education; f/u: follow up; FL: Florida; FT: full time; HNC: head and neck cancer; HRQoL: health related quality of life; hx: history; IC: inclusion criteria; ID: identify; IL: Illinois; IV: independent variables; LOE: levels of evidence; MHQOL: mental health quality of life; MI: mental illness; MO: Missouri; n: sample size; NCI: National Cancer Institute; NJ: New Jersey; NS: non significant; NY: New York; PHQOL: physical health quality of life; pop: population; PSS: perceived social support; pt: patient; QOL: quality of life; SO: significant other; SS: support services; tx: treatment; UK: United Kingdom; USA: United States of America ; X²: Chi square test; v: version; vs: versus; yr: year; α : Cronbach’s alpha; β : slope coefficients; ↑: increased; ↓: decreased; →: leads to; >: greater than; <: less than; =: equals

			Setting: support group meetings					
(Paterson, Jones, Rattray, & Lauder, 2013) Exploring the relationship between coping, social support and health-related quality of life for prostate cancer survivors Country: UK Funding: PhD doctoral fellowship by the University of Dundee, School of Nursing and Midwifery and the Alliance for Self-Care Research. Bias: low level and limited evidence	Social support theory and Buffer theory of social support	Systematic review of LOE III Purpose: ID SS affects coping and QOL	n: 11 studies 3 cross sec 3 intervention 5 prospective longitudinal 0 qualitative Total pop: 1553 Mainly USA studies pop: white, married, and well educated IC: SS measured affecting HRQoL, English, prostate CA pt only EC: study protocol, other CA sites, Setting: not restricted	IVI: SS DV1: HRQoL DV2: coping	Descriptive	Used Endnote X4 Kappa reviewers' consistency	Good level of agreement ($\kappa = 0.922, p < .001$) Received SS not predict HRQoL PSS and satisfaction related to HRQoL PSS and HRQoL mediated by positive coping (Sobels test, $Z = -2.29, p < .05$)	LOE= II Strengths-collection of SS and QOL in prostate CA. theory driven Weaknesses-heterogeneous methodologies, absence of multidimensional inventory of SS Conclusion- weak evidence need more research Highly distressed men/ have inadequate support provisions benefit from SS intervention Application- measure quality verse quantity of SS = PSS
(Matthews, Tejada, Johnson,	Contextual model of	Cross-sectional correlation	n: 248 AA 244 White	IVI: demographics	Demographics	Used Stata./SE v11	Poor PHQOL: unemployed,	LOE= III-3

AA: African American; **avg**: average; **b/w**: between; **BL**: baseline; **BrCA**: breast cancer; **CA**: cancer; **CG**: caregiver; **DS**: depressive symptoms; **DV**: dependent variables; **dx**: diagnosed; **EC**: exclusion criteria; **edu**: education; **f/u**: follow up; **FL**: Florida; **FT**: full time; **HNC**: head and neck cancer; **HRQoL**: health related quality of life; **hx**: history; **IC**: inclusion criteria; **ID**: identify; **IL**: Illinois; **IV**: independent variables; **LOE**: levels of evidence; **MHQOL**: mental health quality of life; **MI**: mental illness; **MO**: Missouri; **n**: sample size; **NCI**: National Cancer Institute; **NJ**: New Jersey; **NS**: non significant; **NY**: New York; **PHQOL**: physical health quality of life; **pop**: population; **PSS**: perceived social support; **pt**: patient; **QOL**: quality of life; **SO**: significant other; **SS**: support services; **tx**: treatment; **UK**: United Kingdom; **USA**: United States of America ; **X²**: Chi square test; **v**: version; **vs**: versus; **yr**: year; **α** : Cronbach's alpha; **β** : slope coefficients; **\uparrow** : increased; **\downarrow** : decreased; **\rightarrow** : leads to; **>**: greater than; **<**: less than; **=**: equals

<p>Berbaum, & Manfredi, 2012)</p> <p>Correlates of quality of life among African American and white cancer survivors</p> <p>Country: USA, IL</p> <p>Funding: grants from the NCI: R01CA775-01A1 and R25CA057699</p> <p>Bias: self reported, AA selected 1st then white to match</p>	<p>HRQoL (Ashing-Giwa, 2005)</p>	<p>Telephone survey study</p> <p>Purpose: assess socio-demographic, clinical, and psychosocial characteristics affecting QOL CA pt.</p> <p>Recruited: hospitals and state CA registry</p>	<p>Population, age 26->75 yr.</p> <p>IC: dx with breast, prostate, or colorectal CA in last 3 yrs.</p> <p>EC: >36 months from dx, other CA site, deceased, non-English speaking</p> <p>Attrition: One time 60-90 minute survey. Dates not given</p> <p>Attrition rate: 19.5%</p> <p>Setting: phone interviews</p>	<p>IV2: clinical characteristics IV3: CA-related stress IV4: psychosocial characteristics</p> <p>DV1: PHQOL DV2: MHQOL</p>	<p>Medical Outcomes Study 36-item Short-form Health survey ($\alpha = 0.84$)</p> <p>Multidimensional Scale of Perceived Social Support ($\alpha = 0.75$)</p> <p>Functional Assessment of Chronic Illness Therapy-Spiritual Characteristics Scale ($\alpha = 0.87$)</p>	<p>X²</p> <p>2-sample Student <i>t</i> test</p> <p>Multivariate regression models</p>	<p>uninsured, comorbidities, ↑ life disruptions due to tx, and ↑ daily stress (Race NS)</p> <p>Poor MHQOL: AA, unemployed, ↑ daily stress, ↑ dx stress, ↑ coping resource use</p> <p>Better MHQOL: ↑ edu, perceived social support, ↑ spirituality scores</p> <p>AA and perceived SS affected MHQOL($\beta = 1.32, p < 0.001$)</p> <p>CA type and gender: NS for both</p>	<p>Strengths-large n and more generalizable, AA pt matched closely with white pt. measured psychosocial variables</p> <p>Weaknesses-mainly self reported, pt knowledge of CA stage, measured stress not valid tool, stress-QOL relationship needs more research</p> <p>Conclusions- ID general and culturally specific predictors of QOL in AA CA pt</p> <p>Application-characteristics involved with QOL- socio-demographics</p>
<p>(Zhou et al., 2010)</p>	<p>Buffering theory of social support</p>	<p>Longitudinal interviews</p>	<p>n: 180 pop: male, age > 50 yr.</p>	<p>IV1: SS IV2: coping DV1: QOL</p>	<p>SS: ENRICHD Social Support Instrument ($\alpha = 0.80$)</p>	<p>Used SPSS v16</p>	<p>QOL associated SS ($\beta = 0.53, p < 0.001$)</p>	<p>LOE= III-2</p>

AA: African American; avg: average; b/w: between; BL: baseline; BrCA: breast cancer; CA: cancer; CG: caregiver; DS: depressive symptoms; DV: dependent variables; dx: diagnosed; EC: exclusion criteria; edu: education; f/u: follow up; FL: Florida; FT: full time; HNC: head and neck cancer; HRQoL: health related quality of life; hx: history; IC: inclusion criteria; ID: identify; IL: Illinois; IV: independent variables; LOE: levels of evidence; MHQOL: mental health quality of life; MI: mental illness; MO: Missouri; n: sample size; NCI: National Cancer Institute; NJ: New Jersey; NS: non significant; NY: New York; PHQOL: physical health quality of life; pop: population; PSS: perceived social support; pt: patient; QOL: quality of life; SO: significant other; SS: support services; tx: treatment; UK: United Kingdom; USA: United States of America ; X²: Chi square test; v: version; vs: versus; yr: year; α : Cronbach's alpha; β : slope coefficients; ↑: increased; ↓: decreased; →: leads to; >: greater than; <: less than; =: equals

<p>Longitudinal effects of social support and adaptive coping on the emotional well being of survivors of localized prostate cancer.</p> <p>Country: USA, FL</p> <p>Funding: NCI grant 1P50CA84944</p> <p>Bias: no control group.</p>		<p>Purpose: how SS and coping affect emotional well-being</p> <p>Recruited: advertisements; referrals, and mailings from state CA registry</p>	<p>IC: survivors localized Prostate CA, radical prostatectomy or radiotherapy <18 months, > 9th grade reading level</p> <p>EC: active hormone tx, hx other CA, mental illness, cognitive impairment.</p> <p>2 yr study study. Attrition rate and explanation not disclosed</p> <p>Interviewed BSL, 3 month, 10 month, and 2 yrs post BSL</p> <p>Setting: not disclosed</p>	<p>DV2: physical function DV3: Demographics</p>	<p>Coping: 28-item Brief COPE ($\alpha = 0.75$)</p> <p>Physical function: EPIC or UCLA-PCI ($\alpha = 0.71-0.80$)</p> <p>QOL: FACT-G (27-item) ($\alpha = 0.83$)</p>	<p>Independent samples <i>t</i> test</p> <p>Pearson zero-order correlation</p> <p>Sobel test</p> <p>Post hoc analyses</p>	<p>Coping associated SS ($\beta = 0.36, p < 0.01$)</p> <p>↑ SS = ↑ QOL ($p < 0.01$)</p> <p>Ethnicity NS</p>	<p>Strengths-critical post-tx period, longitudinal study, prostate CA,</p> <p>Weaknesses-SS prior to CA tx not measured, other forms of SS not asked, n too small for Sobel test</p> <p>Conclusions- SS predictor of QOL in prostate CA men</p> <p>Application- SS networking and coping skills needed in critical post tx period, support SS groups ↑ QOL</p>
<p>(Applebaum et al., 2014)</p>	<p>↓ optimism allow for SS to have ↑</p>	<p>Cross section of pts in RCT</p>	<p>n: 168 Pop mainly white female</p>	<p>IVI: Optimism IV2: SS</p>	<p>Life Orientation Test-Revised</p>	<p>Used SPSS v20</p>	<p>SS and optimism</p>	<p>LOE= III-3</p>

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<p>Optimism, social support, and mental health outcomes in patients with advanced cancer.</p> <p>Country: USA, NY</p> <p>Funding: NCI grant 1RO1CA128187 and T32CA009461-26</p> <p>Bias: convenience sampling of those agreed to psychotherapy</p>	<p>impact on anxiety, depression, hopelessness, and QOL</p>	<p>Meaning-Centered Group Psychotherapy (MCGP) prior to therapy</p> <p>Purpose: role of optimism as a moderator of the relationship between social support and anxiety, depression, hopelessness, and QOL among advanced CA pts</p> <p>Recruited: outpt CA clinics in NY, posted flyers or physician referral b/w 8/2007-5/2012</p>	<p>(>70%), age >18 yr.</p> <p>IC: stage III or IV solid tumor CAs or non-Hodgkin's lymphoma, ambulatory, English speaking</p> <p>EC: cognitive impairment, psychosis, or physical limitation</p> <p>Attrition: 2 yr study. Attrition rate explanation not disclosed</p> <p>Setting: psychotherapy office</p>	<p>IV3: demographics</p> <p>DV1: hopelessness</p> <p>DV2: anxiety</p> <p>DV3: depression</p> <p>DV4: QOL</p>	<p>(LOT-R), 10-item scale ($\alpha = 0.78$)</p> <p>Hospital Anxiety and Depression Scale (HADS) is a 14-item self-rated</p> <p>Beck Hopelessness Scale 20 true/false questions (KR-20 mostly in the .90s)</p> <p>Duke-UNC Functional Social Support Questionnaire (DUFSS) 8-item multidimensional ($\alpha = 0.80-0.85$) test-retest reliability (0.50-0.77)</p> <p>McGill Quality of Life Questionnaire ($\alpha > 0.70$)</p>	<p>Separate hierarchical regression analyses</p> <p>Steps</p> <p>1: demographic variables</p> <p>2: added optimism</p> <p>3: added SS,</p> <p>4: added the interaction of optimism and SS.</p> <p>Pearson product moment correlation coefficients</p>	<p>moderately correlated ($r=0.34$, $p<0.01$)</p> <p>Optimism significantly associated ↓ anxiety, depression, hopelessness and ↑ QOL ($\beta = -0.500$, $\beta = 0.611$, $\beta = -0.659$, $\beta = 0.538$, $ps<0.001$)</p> <p>↑ SS and ↑ QOL ($\beta = 0.204$, $p = 0.003$)</p>	<p>Strengths- large n, IV demographics that reflect SS, QOL, and optimism</p> <p>Weaknesses- demographics not generalizable, convenience sampling, participants agreed for psychotherapy</p> <p>Conclusions- SS and optimism important to QOL</p> <p>Application- screening for these variables to identify those with low SS and optimism to SS services</p>
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<p>(Leow, Chan, & Chan, 2014)</p> <p>Predictors of Change in Quality of Life of Family Caregivers of Patients Near the End of Life With Advanced Cancer</p> <p>Country: Singapore</p> <p>Funding: Singapore Cancer Society (grant WBS:R-545-000-040-592)</p> <p>Bias: High attrition, different medical system, convenience sample</p>	<p>Buffering Theory of social support</p>	<p>Longitudinal survey, convenience sample</p> <p>Purpose: ID change in QOL, SS and spirituality and predictors of QOL in CGs of CA hospice</p> <p>Conducted: 7/2011 to 6/2012</p> <p>Recruited: staff referral from 4 hospice homes, CG psycho-edu classes by nurse</p>	<p>n: 93 pop: avg age 49</p> <p>50% FT work. 70% female, 61% caring for their parents</p> <p>IC: age > 21 yr. primary family CG of stage 4 CA hospice pt, English or Mandarin</p> <p>EC: domestic helpers, CG with MI cognitive impairment</p> <p>Attrition: 48.7% due to pt death, illness, or CG to busy</p> <p>2-month study. Attrition rate explanation not disclosed</p>	<p>IV1: socio-demographics</p> <p>DV1: QOL</p> <p>DV2: SS</p> <p>DV3: Spirituality</p> <p>DV4: pt caregiving demand</p>	<p>Social Support Questionnaire 12-item, 6-point Likert scale ($\alpha = .91-.93$)</p> <p>Caregiver QOL 35 items, 5-point Likert scale (test-retest: 0.95, $\alpha = .91$), validity of 89%.</p> <p>Caregiving Demands Scale. 5 items, 4-point Likert scale</p> <p>Spiritual Perspective Scale 10 items on 6 point Likert scale (test-retest of 0.83 to 0.93, $\alpha > .90$) content validity of 97%</p>	<p>Used SPSS v18</p> <p>X^2</p> <p>Paired Student <i>t</i> test</p> <p>Independent <i>t</i> test</p> <p>Analysis of variance (ANOVA)</p> <p>Correlations</p>	<p>↑ # of SS and SS satisfaction ($r = 0.36, p < .000$)</p> <p>↑ SS satisfaction: CG female, married, older, with chronic illness, pt older, hospitalized < 2 months ago.</p> <p>↑ # of SS: CG with high edu and had religion</p> <p>CG ↑ SS satisfaction ($\beta = .60, p = .000$) + religion ($\beta = .55, p = .001$) Had ↑ QOL</p> <p>CG of female only CA ↓ QOL ($\beta = -.33, p = .03$)</p>	<p>LOE= III-2</p> <p>Strengths-CG and pt surveyed, over 2 yrs,</p> <p>Weaknesses-high attrition rate, pt death ↑ unpredictable (28% deaths),</p> <p>Conclusions- SS important to CG QOL</p> <p>Application- CG described and importance of CG SS satisfaction.</p>
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			Setting: home hospice					
			Baseline and 2 months post					
(Morse, Gralla, Petersen, & Rosen, 2014)	Social support theory	Cross-sectional survey design	n: 3,723 pop: avg age 58, white (94%), female (70%), partnered (76%), not living alone (83%), > some college (91%), pt (90%), hormonal CA (65%)	IV1: demographics DV1: PSS DV2: Topics importance DV3: group satisfaction	A list of 26 Possible topics Multidimensional Scale of Perceived Social Support 12-item (α not reported)	Used (not mentioned) X^2 Two-sample t test Fisher's exact test	pt vs CG: pt \uparrow PSS [t(3,448) = 3.22, $p < 0.001$] PSS positive in both groups Important topics pt: sexuality CG: dealing with anxiety, depression, stress and stress management, pain and its control, changes in relationships and roles, end-of-life care, and bereavement	LOE= III-3 Strengths- largest n survey Weaknesses- not demographics were compared with PSS scores, demographics not transfer well to general pop, internet only survey, self reported Conclusions- different topics of importance, few in SS groups and half not satisfied. Application- support directed to pt not SO, topics differ in importance, and many are not satisfied with SS groups (no explanation/ correlations)
Preferences for cancer support group topics and group satisfaction among patients and caregivers		Purpose: explore pt and CG preferences for group content, guide development and implementation of CA SS groups	IC: users of NexCura Cancer Profiler website CA pt and CG, age > 18 yr					
Country: USA, NY		Recruited: e-mail solicitation	EC: unfinished survey					
Funding: NexCura and North Shore Long Island Jewish Health System			Attrition:					
Bias: Non-response number unavailable								

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			Attrition rate/ explanation not disclosed				SS group satisfaction (25% of n): pt: 43% CG: 33%	
(Pulgar, Alcala, & Reyes del Paso, 2015)	Neg emotional states + ↓ optimism and SS= ↑ stress and ↓ QOL	Cross sectional study Individual interviews performed by an expert clinical psychologist Purpose: QOL predictors via socio- demographics Recruited: from hospital staff	n: 69 pop: most age 40 ->70 yr, married, <1yr from dx, currently receiving chemo only IC: dx hematological CA, adults EC: in remission, admitted to hospital, cognitive deficits Attrition: No refusals Setting: hospital	IV1: socio- demographics IV2: DV1: QOL DV2: SS DV3: optimism DV4: stressors	Short-Form Health Survey (SF-36, Version 1-Spanish) ($\alpha = 0.7$ and 0.94) Social Support Scale (AS-25) ($\alpha = 0.87$) Life Orientation Test ($\alpha = 0.87$) Hospital Anxiety and Depression Scale ($\alpha = 0.82$ - 0.84) Stressors and Coping Strategies for Cancer Inventory ($\alpha = 0.80$)	Hierarchical multiple regression analysis Step-wise multiple regression analysis collinearity statistics	Predictors: depression, social support, optimism, neg. emotions, total # disease-related stress situations, coping strategies, relaxation, and passivity. Age neg. association to physical and social function High edu inverse association to pain ($\beta = 0.29$, r_2 = 0.06, $p = .015$) CA dx is negatively associated with general health (β = - 0.34, r_2 = 0.11, $p = .003$) Depression	LOE= III-3 Strengths-regression analysis of charateristics of CA QOL. Better if n was >100. Weaknesses-small n, too many predictors, unable to see causations, PSS results limited Conclusions-physical and social areas are greatly affected in CA pts, age and time ↓ QOL ↑SS, ↑edu, partner = ↑QOL Application- suggests strengthening social support networks, which improves vitality

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							explains 36% of the variance Illness 27% of the variance PSS is positively associated with vitality, explains 12% of the variance	
(Sammarco & Konecny, 2010) Quality of life, social support, and uncertainty among Latina and Caucasian breast cancer survivors: a comparative study Country: USA, NY and NJ Funding: Research Foundation of the City University of New York: PSC-CUNY grant #68169-00-37	The Mishel Uncertainty in Illness Theory (Mishel, 1988, 1990) and the Ferrans Conceptual Model of QOL (Ferrans, 1996)	Descriptive, comparative study Purpose: examine differences in Latina and Caucasian BrCA survivors in PSS, QOL, uncertainty, and demographics Mailed questionnaire Recruited: staff gave study packets to pt.	n: 280 total 182 Caucasian and 98 Latina pop: avg age 57 yr. IC: adult, Latina or Caucasian BrCA survivor EC: any other ethnicity Attrition: 31% response rate (one time survey) Attrition rate explanation not disclosed	IV1: demographics DV1: uncertainty DV2: PSS DV3: QOL	Mishel Uncertainty in Illness Scale-Community Form ($\alpha = 0.91$) The Ferrans and Powers QOL Index-CA Version III ($\alpha = 0.95$) Social Support Questionnaire ($\alpha = 0.93$)	Stats program not disclosed, statistician used X^2 Mean scores SDs and ranges Independent sample t tests	Ethnicity and marital status ($X^2 [5, n = 280] = 20.27, p = 0.01$) White married: 69% Edu and ethnicity ($X^2 [3, n = 279] = 24.62, p < 0.001$) Only primary edu Latina: 17% Ethnicity and depression ($X^2 [1, n = 278] = 18.71, p < 0.001$) White \uparrow PSS ($p = 0.04$)	LOE= III-3 Strengths- USA, compares whites to Latinas, Weaknesses- convenience sampling, assuming family and cultural differences (not questioning authority, illness is punishment) are reasons for Conclusions- cultural values, comorbidities, and edu level likely influence PSS uncertainty, and QOL Application- remove barriers for family involvement and understand personal

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Bias: cross-section design			Setting: private hospitals and American CA units NY& NJ				Latina ↑ uncertainty (p = < 0.001) White ↑ QOL (p= 0.011)	limiting beliefs for culturally competent care
(Leung, Pachana, & McLaughlin, 2014) Social support and health-related quality of life in women with breast cancer: A longitudinal study Country: Australia Funding: Australian Government Department of Health and Ageing Bias: different medical system,	Buffering model of social support	Longitudinal Prospective cohort study Purpose: relationships among a dx of BrCA, SS, and (HRQOL) 3 yrs before dx (baseline) and 3 years after (f/u) Recruited: Australian Medicare database mailed surveys	n: 412 pop: age 18-75 yr. IC: 1946–1951 birth cohort of the Australian Longitudinal Study on Women’s Health who self-reported a new diagnosis of BrCA between 1998 and 2007 EC: surveys with missing data Surveys from 1996 to 2010 Attrition: 17% 6 yr study.	IV1: Time IV2: socio-demographics DV1: QOL DV2-4: PSS DV2: emotional/informational support DV3: affectionate support/positive social interaction DV4: tangible support	Self reported 19-item Medical Outcomes Study Social Support Survey (α = 0.90–0.96) Medical Outcomes Study 36-item Short Form Health Survey	Used SPSS v19 Structural equation model ANOVAs Pearson’s correlation	No change with PSS over time Married = ↑ PSS and ↑ QOL High PSS (baseline) predicted higher QOL at f/u	LOE= III-2 Strengths- collected pre-dx HRQoL, rural pop and urban, highly diverse population Weaknesses- HRQoL not CA version, other variables (CA stage), poor mental health underrepresented, did not follow men CAs Conclusions- better social support was associated with better quality of life Application- emotional/informational SS and affectionate SS/positive social interaction, rather than tangible SS, were more important in improving QOL

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			Attrition related to less edu, not being born in Australia, and being a current smoker, in all cohorts, and with poorer health in the older cohort					
			Setting: home					
(Huang & Hsu, 2013) Social support as a moderator between depressive symptoms and quality of life outcomes of breast cancer survivors. Country: Taiwan Funding: not disclosed Bias: different medical system	Concept of social support (Cohen and Wills, 1985) SS related to DS and QOL	Model based, descriptive cross-sectional Purpose: examine demographics DS, PSS, and QOL in BrCA survivors, and whether SS moderated effects of DS on QOL Recruited: Face to face survey interviews, physician referral	n: 150 pop: avg age 52, married, < 9 yrs edu., stage II BrCA IC: BrCA survivor, > 18 yr age, Chinese or Taiwanese-speaking EC: dementia, psychosis, severe concomitant disease, extensive care Attrition:	IV1: demographics DV1: DS DV2: PSS DV3: QOL	Center for Epidemiological Studies- Depression ($\alpha = 0.94$) Interpersonal Support Evaluation List ($\alpha = 0.82-0.86$) Medical Outcomes Study 36-Item Short Form Health Questionnaire ($\alpha = 0.75-0.89$)	Used SPSS v17 Pearson product moment correlations t-test ANOVA Structural equations and hierarchical regression analyses	35% n had DS. \uparrow Age = \downarrow QOL and \uparrow DS \uparrow Edu = \uparrow QOL Married = \downarrow DS \uparrow QOL= \uparrow PSS \uparrow PSS = \downarrow DS PSS explained 30% of the variance on QOL	LOE= III-3 Strengths- PSS, DS, and QOL complex moderation models Weaknesses- no dx depression, unable to generalize (Eastern vs Western med) Conclusions- DS –PSS–QOL Application- PSS is mediator between DS and QOL, devise effective programs that can address distressed DS and QOL

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			Attrition rate explanation not disclosed					
			Setting: two teaching hospitals, outpt departments					
(Salonen, Rantanen, Kellokumpu-Lehtinen, Huhtala, & Kaunonen, 2014) The quality of life and social support in significant others of patients with breast cancer: A longitudinal study. Country: Finland Funding: Competitive research funding of the Pirkanmaa Hospital District Bias: different medical system	Ferrans's definition of QOL and Kahn's (1979) theory of social support	Quasi-random longitudinal study Purpose: QOL and received SS changes in SO of BrCA pt 1 wk and 6 months post surgery SO did not get intervention (only BrCA pt got physiotherapist) Recruited: by nurses in 2 hospitals after BrCA surgery	n: 165 pop: avg age 52, mainly men/spouses, employed, no young children IC: SO of BrCA surgery participating in BrCA pt longitudinal study EC: minority Attrition: 6-month study. Attrition rate or explanation not disclosed Setting: survey	IVI: demographics IV2: DV1: QOL DV2: received SS from network DV3: received SS from nurses	Ferrans and Powers Quality of Life Index – CA Version 70-item Kahn's scale (network SS) ($\alpha = 0.78$ to 0.88) Social support from nurses' scale ($\alpha = 0.74$ to 0.90)	Used SPSS v20 Pearson's chi-square test or Fisher's exact test Mann-Whitney U-test Logistic regression models Wilcoxon's Signed Ranks test	Sources of SS: spouse/partner, children and friends Retired ↓ QOL (OR 3.62, 95% CI 1.07–12.2) ↑ Risk in ↓ socio-economic QOL (OR 3.33 95% CI 1.02–10.9) SO of pt receiving intervention ↓ socio-economic QOL (p= 0.01)	LOE= III-1 Strengths- validated QOL scale, longitudinal design Weaknesses- sensitivity of QOL scale, no BL measurements prior to BrCA surgery; report of nearly significant = need longer timeline Conclusions- pt socio-economic QOL effects SO QOL. SO did not receive SS they needed during study. Need interventions ↑ QOL for family Application- evaluating SO QOL is essential when evaluating CA pt QOL

AA: African American; **avg**: average; **b/w**: between; **BL**: baseline; **BrCA**: breast cancer; **CA**: cancer; **CG**: caregiver; **DS**: depressive symptoms; **DV**: dependent variables; **dx**: diagnosed; **EC**: exclusion criteria; **edu**: education; **f/u**: follow up; **FL**: Florida; **FT**: full time; **HNC**: head and neck cancer; **HRQoL**: health related quality of life; **hx**: history; **IC**: inclusion criteria; **ID**: identify; **IL**: Illinois; **IV**: independent variables; **LOE**: levels of evidence; **MHQOL**: mental health quality of life; **MI**: mental illness; **MO**: Missouri; **n**: sample size; **NCI**: National Cancer Institute; **NJ**: New Jersey; **NS**: non significant; **NY**: New York; **PHQOL**: physical health quality of life; **pop**: population; **PSS**: perceived social support; **pt**: patient; **QOL**: quality of life; **SO**: significant other; **SS**: support services; **tx**: treatment; **UK**: United Kingdom; **USA**: United States of America ; **X²**: Chi square test; **v**: version; **vs**: versus; **yr**: year; α : Cronbach's alpha; β : slope coefficients; \uparrow : increased; \downarrow : decreased; \rightarrow : leads to; $>$: greater than; $<$: less than; $=$: equals

			completed at home, mailed back					
(Penedo et al., 2012)	PSS predicts QOL beyond disease and tx characteristics	Prospective study Purpose: changes of PSS from pre-tx to post-tx to predict QOL among HNC pt Recruited: CA clinic during appointment	n: 32 pop: avg age 57, mainly white men, married, employed, surgery only tx IC: HNC (stages I-IV) awaiting surgery or radiation, 9th-grade reading level EC: chemotherapy tx, cognitive impairment, active psychiatric symptoms in last 3 months Attrition: 6-week study. Attrition rate: 22% due to tx changes,	IVI: demographics DV1: QOL DV2: PSS	ENRICHD Social Support instrument ($\alpha = 0.88$) Functional Assessment of Cancer Therapy-Head & Neck ($\alpha = 0.80$)	Used SPSS v14 Paired-samples t-tests Pearson correlations One-way analysis of variance Hierarchical regression analyses	Stages III-IV ↓ QOL (F [1,27] = 5.0; $p < .04$) tx with radiation ↓ QOL (F [1,29] = 5.0; $p < .04$) Younger age and employment ↑ QOL PSS related to post-tx QOL (r = 0.51; $p < .01$) PSS ↓ post tx (F [31] = -2.71, $p < .01$). Adjustments for dx and tx characteristics: PSS predictor of post-tx QOL ($\beta=0.47$, $p < .01$) Unidirectional relationship between PSS and QOL	LOE= III-3 Strengths- validated QOL and PSS scale, tested prior to tx. Weaknesses- small and heterogeneous n; short term f/u, no controls Conclusions- ↑ social isolation risk factor of ↓ QOL post-tx. PSS important target for interventions Application- PSS changes with tx, need interventions to preserve SS networks prior to tx

AA: African American; avg: average; b/w: between; BL: baseline; BrCA: breast cancer; CA: cancer; CG: caregiver; DS: depressive symptoms; DV: dependent variables; dx: diagnosed; EC: exclusion criteria; edu: education; f/u: follow up; FL: Florida; FT: full time; HNC: head and neck cancer; HRQoL: health related quality of life; hx: history; IC: inclusion criteria; ID: identify; IL: Illinois; IV: independent variables; LOE: levels of evidence; MHQOL: mental health quality of life; MI: mental illness; MO: Missouri; n: sample size; NCI: National Cancer Institute; NJ: New Jersey; NS: non significant; NY: New York; PHQOL: physical health quality of life; pop: population; PSS: perceived social support; pt: patient; QOL: quality of life; SO: significant other; SS: support services; tx: treatment; UK: United Kingdom; USA: United States of America ; X²: Chi square test; v: version; vs: versus; yr: year; α : Cronbach's alpha; β : slope coefficients; ↑: increased; ↓: decreased; →: leads to; >: greater than; <: less than; =: equals

			death or withdrew					
			Setting: clinic					
(Waters, Liu, Schootman, & Jeffe, 2013) Worry about cancer progression and low perceived social support: implications for quality of life among early-stage breast cancer patients Country: USA, MO Funding: NCI and BrCA Stamp Fund (R01CA102777) and NCI Cancer Center Support Grant (P30 CA91842) Bias: n did not worry	Worry + PSS affects QOL	Cross-sectional and longitudinal with controls Purpose: cross-sectional and longitudinal Inter-relationships among worry about CA progression, PSS, and QOL in BrCA Conducted: 4 computer-assisted phone interviews 4–6 weeks (T1), 6 months (T2), 1 year (T3), and 2 years (T4) following definitive surgery. Recruited: from MO hospitals	n: 480 pop: avg age 58 yr. mainly white, least some college edu, no hx DS IC: 1 st primary early-stage BrCA (stages 0–IIA) b/w 10/2003 to 6/2007, English speaking, age >40, definitive surgery EC: hx other CAs, chemotherapy age > 65, cognitive impairment, need for additional CA treatment Attrition: 12% 2 yr study.	IV1: Worry IV2: PSS IV3: demographics IV4: anxiety DV1: QOL	Medical Outcomes Study Social Support Survey 19-item ($\alpha=0.97$) Functional Assessment of CA Therapy-Breast v 4 RAND 36-item Health Survey ($\alpha=0.77 - 0.92$) State-Trait Anxiety Inventory ($\alpha=0.93$)	SAS statistical software v9.3 Spearman rank-order correlation Multivariate analysis of variance (MANOVA) and multivariate analysis of covariance (MANCOVA) Post hoc test X ² Paired & unpaired Student <i>t</i> test	70% of n not worried about CA progressing worry → QOL (Wilks' $\lambda=0.94$, F[8,455]04.1, $p<.0001$) PSS → QOL ($\lambda=0.86$, F[24,1,320]02.9, $p<.0001$) But not for the interaction worry + PSS ($\lambda=0.94$, F[24,1,320]01.2, $p=0.24$). T1-T3: worry, ↓ PSS effecting QOL still seen T4 all significant negative effects of greater worry and lower PSS had dissipated	LOE= III-2 Strengths-design showing one time survey and changes over time, Weaknesses- very specific sample, worry single-item measure, final interview = healthier pt Conclusions- ↑ worry and/or ↓ PSS = ↓ QOL, support needs lessen over time, interaction not clarified Application- PSS does not related to levels of worry, but both independently are related to levels of QOL. PSS is not stable individual characteristic

AA: African American; **avg**: average; **b/w**: between; **BL**: baseline; **BrCA**: breast cancer; **CA**: cancer; **CG**: caregiver; **DS**: depressive symptoms; **DV**: dependent variables; **dx**: diagnosed; **EC**: exclusion criteria; **edu**: education; **f/u**: follow up; **FL**: Florida; **FT**: full time; **HNC**: head and neck cancer; **HRQOL**: health related quality of life; **hx**: history; **IC**: inclusion criteria; **ID**: identify; **IL**: Illinois; **IV**: independent variables; **LOE**: levels of evidence; **MHQOL**: mental health quality of life; **MI**: mental illness; **MO**: Missouri; **n**: sample size; **NCI**: National Cancer Institute; **NJ**: New Jersey; **NS**: non significant; **NY**: New York; **PHQOL**: physical health quality of life; **pop**: population; **PSS**: perceived social support; **pt**: patient; **QOL**: quality of life; **SO**: significant other; **SS**: support services; **tx**: treatment; **UK**: United Kingdom; **USA**: United States of America ; **X²**: Chi square test; **v**: version; **vs**: versus; **yr**: year; α : Cronbach's alpha; β : slope coefficients; \uparrow : increased; \downarrow : decreased; \rightarrow : leads to; $>$: greater than; $<$: less than; $=$: equals

			Attrition rate explanation not disclosed					
			Setting: medical centers					

AA: African American; **avg:** average; **b/w:** between; **BL:** baseline; **BrCA:** breast cancer; **CA:** cancer; **CG:** caregiver; **DS:** depressive symptoms; **DV:** dependent variables; **dx:** diagnosed; **EC:** exclusion criteria; **edu:** education; **f/u:** follow up; **FL:** Florida; **FT:** full time; **HNC:** head and neck cancer; **HRQoL:** health related quality of life; **hx:** history; **IC:** inclusion criteria; **ID:** identify; **IL:** Illinois; **IV:** independent variables; **LOE:** levels of evidence; **MHQOL:** mental health quality of life; **MI:** mental illness; **MO:** Missouri; **n:** sample size; **NCI:** National Cancer Institute; **NJ:** New Jersey; **NS:** non significant; **NY:** New York; **PHQOL:** physical health quality of life; **pop:** population; **PSS:** perceived social support; **pt:** patient; **QOL:** quality of life; **SO:** significant other; **SS:** support services; **tx:** treatment; **UK:** United Kingdom; **USA:** United States of America ; **X²:** Chi square test; **v:** version; **vs:** versus; **yr:** year; **α:** Cronbach’s alpha; **β:** slope coefficients; **↑:** increased; **↓:** decreased; **→:** leads to; **>:** greater than; **<:** less than; **=:** equals

Table 2

Appendix G Synthesis Table: Characteristics related to QOL from social support

Study	Times the population was surveyed	CA pt	CG	Gender	Occupation	Educational Level	Income	Race/ethnicity	Employment	Married/partnered	Insurance	Age	Comorbidities	Depression	CA type	CA stage	Tx type	Dx date/time as a CG	Religion	Optimism	Social support conclusion	Positive correlation b/w PSS and QOL	
Brand (2014)	1		X	NS	NS	NS	NS	NS	NS	NS	n/a	NS	NS	n/a	n/a	n/a	n/a		n/a	+	↑BF→ ↑PSS → ↑QOL	X	
Paterson (2013) Literature review	n/a	X	X	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	-	Prostate only	n/a	n/a	n/a	n/a	n/a		Only PSS; + due to ↑ coping	X
Matthews (2012)	1	X		NS	n/a			AA ↓		NS	-	NS	-	n/a		n/a	n/a	NS	+	n/a		↑PSS=↑QOL	X
Zhou (2010)	2	X		M only	n/a	NS	NS	NS	n/a	NS	n/a	NS	n/a	n/a	Prostate only	n/a		NS	n/a	n/a		PSS predicts QOL; mediated by coping	X
Applebaum (2014)	1	X		NS	n/a	NS	n/a	NS			n/a	NS			NS	NR	n/a	n/a	NR	NS		Optimism ↑ PSS	X
Leow (2014)	2		X	M ↓	n/a	NS	NS	NS	NS	NS	n/a	NS	NS	n/a	NS	n/a	n/a		+	n/a		32% used friends; 8% spouse	X
Morse (2014)	1	X	X		n/a		n/a		n/a		n/a	NR	n/a	n/a		n/a	n/a		n/a	n/a		25% used online SG	Not tested, assumed
Pulgar (2015)	1	X		NS	n/a	+	NS	NS	n/a	+	n/a	-		-	NS	n/a	NS	-	n/a			Vitality ↑ PSS	X
Sammarco (2010)	1	X		F only	NS	+		Lati na ↓			+	NS	+	-	BrCA only	CA S only	NS	NS	n/a	n/a		Latina ↑ spouse/family SS	X

Leung (2014)	3	X		F only	n/a	NS	n/a	NS	n/a	+	n/a	n/a		-		n/a	n/a	-	n/a	n/a	SS was Spouses	X
Huang (2013)	1	X		F only	n/a	+	+	n/a	n/a	NS	n/a	-	n/a	-	BrCA only	-	NS	NS	n/a	n/a	PSS ↓ DS; TA NS	X
Salonen (2014)	2		X	NS	n/a	NS	n/a	n/a			n/a	NS	-	n/a	BrCA only	n/a	n/a	n/a	n/a	n/a	85% used Spouse/partners	X
Penedo (2012)	2	X		NR	n/a	NR	NR	NR		NR	n/a	-	n/a	n/a	HNC only	-		-	n/a	n/a	PSS changes with time and tx	X
Waters (2013)	4	X		F only	n/a	NS	n/a	NS	n/a	NR	n/a	-	-	-	BrCA only	Early stage only		-	n/a	n/a	Worry ↓ PSS	X
Correlation found (a)				2	0	5	3	3	5	6	2	4	7	7	3	2	3	7	2	2		13
NS, NR (b)				6	2	8	5	8	2	7	0	8	2	0	3	1	3	4	1	1		0
n/a, other				5	12	1	6	3	7	1	12	2	5	7	8	11	8	3	11	11		1
% of review studies support [a ÷ (a+b)]				25	0	38	38	27	71	46	100	33	77	100	50	66	50	63	66	66		92
CA pt only studies																						
Correlation found				0	0	4	3	2	4	4	2	4	5	6	2	2	3	4	1	1		
NS, NR				4	1	5	3	6	0	5	0	4	0	0	2	1	3	4	1	1		
n/a, other				5	8	0	3	1	5	0	7	1	3	3	5	6	3	1	7	7		
% of these studies support				0	0	45	50	25	100	45	100	50	100	100	50	66	50	50	50	50		100

AA: African American; avg: average; b/w: between; BL: baseline; BrCA: breast cancer; CA: cancer; CG: caregiver; DS: depressive symptoms; DV: dependent variables; dx: diagnosed; EC: exclusion criteria; edu: education; f/u: follow up; FL: Florida; FT: full time; HNC: head and neck cancer; HRQoL: health related quality of life; hx: history; IC: inclusion criteria; ID: identify; IL: Illinois; IV: independent variables; LOE: levels of evidence; MHQOL: mental health quality of life; MI: mental illness; MO: Missouri; n: sample size; NCI: National Cancer Institute; NJ: New Jersey; NS: non significant; NY: New York; PHQOL: physical health quality of life; pop: population; PSS: perceived social support; pt: patient; QOL: quality of life; SO: significant other; SS: support services; tx: treatment; UK: United Kingdom; USA: United States of America ; X²: Chi square test; v: version; vs: versus; yr: year; α: Cronbach’s alpha; β: slope coefficients; ↑: increased; ↓: decreased; →: leads to; >: greater than; <: less than; =: equals

Appendix E: *Figure 2*

Wilson and Cleary's (1995) health-related quality of life conceptual model (Rodriguez, Mayo, & Gagnon, 2013, p. 1791)

Appendix F: *Figure 3*

Permission needed to reprint.

Appendix G

Demographics

Please select one choice for each question, unless otherwise noted

1. Your age:

- 1-18 years of age
- 18-24 years of age
- 25-39 years of age
- 40-55 years of age
- 56-69 years of age
- 70+ years of age

2. Your gender:

- Male
- Female
- Other (please specify): _____

3. Relationship status: You are currently...

- Single
- Long term live in partnership
- First marriage
- Remarried following widowhood
- Remarried following dissolution of previous marriage
- Separated
- Divorced
- Widowed

4. Do you live alone?

- Yes
- No

5. What is your Race?

- White
- Black or African American
- Asian
- Native American and Alaska Native
- Native Hawaiian and other Pacific Islander

6. Ethnicity: Are you Hispanic/ Latino?

- Yes
- No

7. Highest education level completed

- Primary (including no formal education)

- GED
- High school
- Some college
- 2 year college
- 4 yr university
- Masters/doctorates program

8. Your current work status: (check all that apply)

- Retired
- Unemployed
- Working full time
- Part time
- Leave of absence
- Short term disability
- Long term disability
- Student
- Looking after home/family

9. Are you a Veteran?

- Yes
- No

10. Connection to the Community: I _____ diagnosed with cancer

- Am the person
- Have a spouse/partner
- Have a child
- Have a parent
- Have a family member
- Have a friend
- Other: _____

If you have not been diagnosed with cancer: skip this section and go to question #17:

11. Month and year you were first diagnosed with cancer: _____/_____

12. Month and year you were diagnosed with reoccurrence: _____/_____

N/A

13. What type of cancer do you have? Example: breast, prostate, small cell carcinoma, etc.:

14. What is your current cancer stage?

- 0: Cancer hasn't spread
- I: Cancer limited to the tissue of origin, evidence of tumor
- II: Limited local spread of cancerous cells
- III: Extensive local and regional spread
- IV Cancer has spread beyond the lymph nodes into other parts of the body (metastasized)
- Remission (cancer free < 5 years)
- Survivor (cancer free > 5 years)
- Other
- Unknown

15. What cancer treatment type did you have type within the last year: select all that apply

- Surgery
- Radiation
- Chemotherapy
 - Oral
 - Intravenous
- Hormone therapy
- Biological therapies
- Bisphosphonates
- Bone marrow
- Stem cell transplants
- Alternative
- Other
- None

16. To what extent do you feel you are in control with your health care?

0 (not at all) – 5 (complete control)

- 0 (not at all)
- 1
- 2
- 3
- 4
- 5 (complete control)

Services

17. Month and year you started coming to the Community: _____ / _____

18. How often do you attend programs associated with this organization?

- I have not attended any services within the last year (since January 2015)
- Once year
- Once a month
- Once a week
- _____ days a week
- Everyday
- Other _____

19. What programs have you attend in the last year? Select all that applySupport services

Newcomer meeting
 Participant support group
 Living with loss
 Family support group
 Learn and Support Group- Diagnosis specific groups
 Surviving and thriving
 Living with loss
 Youth and Family Support- Kid Support, Family Connect, Teen Talk

Education

Educational Talks- one speaker
 Educational seminar- multiple speakers
 Cancer, genetics, and the family tree
 Lunch and learn – held at Banner
 Mind, Body Connection Retreat

Healthy lifestyle activities

Gentle yoga
 Tai Chi
 Fit for life series
 Walking club
 Qi Gong
 Zumba
 Jin Shin Jyutsu
 Journey to wholeness
 Peaceful breath and relaxation
 Drumming
 Clay class
 Panting Class
 Cooking for Health/Life
 Cooking Demonstrations- Discover Healing Power of Food

Social connections

- Bunco
- Social Outings
- Walking Club
- Knitting
- Teen Social Activities
- Book club
- Potluck
- Community Social Events – Family Day of Hope, Red Balloon, Tribute Tree

Other (please explain): _____

20. Referring to previous Question# 19, how often do you attend these programs?

Select one for each program type

Program type	Never /Other	Rarely	Less than once a month	One or two times a month	About once a week	Two or three times a week	Most days
Support Services	0	1	2	3	4	5	6
Education	0	1	2	3	4	5	6
Healthy Lifestyle Activities	0	1	2	3	4	5	6
Social Connections	0	1	2	3	4	5	6

Appendix H

QUALITY OF LIFE SCALE (QOLS)

Name:

Age:

Date (mm/dd/yyyy):

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

	Delighted	Mostly Pleased	Satisfied	Mixed	Mostly Dissatisfied	Unhappy	Terrible
1. Material comforts home, food, conveniences, financial security	7	6	5	4	3	2	1
2. Health – being physically fit and vigorous	7	6	5	4	3	2	1
3. Relationships with parents, siblings & other relatives – communicating, visiting, helping	7	6	5	4	3	2	1
4. Having and rearing children	7	6	5	4	3	2	1
5. Close relationships with spouse or significant other	7	6	5	4	3	2	1
6. Close friends	7	6	5	4	3	2	1
7. Helping and encouraging others, volunteering, giving advice	7	6	5	4	3	2	1
8. Participating in organizations and public affairs	7	6	5	4	3	2	1
9. Learning – attending school, improving understanding, obtaining additional knowledge	7	6	5	4	3	2	1
10. Understanding yourself – knowing your assets and limitations – knowing what life is about	7	6	5	4	3	2	1
11. Work – job or in home	7	6	5	4	3	2	1
12. Expressing yourself creatively	7	6	5	4	3	2	1
13. Socializing – meeting other people, doing things, parties, etc	7	6	5	4	3	2	1
14. Reading, listening to music, or observing entertainment	7	6	5	4	3	2	1
15. Participating in active recreation	7	6	5	4	3	2	1
16. Independence, doing for yourself	7	6	5	4	3	2	1

Sub-total (for internal use only)							
--	--	--	--	--	--	--	--

Total score:

Appendix I

Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
 Circle the "2" if you **Strongly Disagree**
 Circle the "3" if you **Mildly Disagree**
 Circle the "4" if you are **Neutral**
 Circle the "5" if you **Mildly Agree**
 Circle the "6" if you **Strongly Agree**
 Circle the "7" if you **Very Strongly Agree**

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

Appendix J



EXEMPTION GRANTED

Donna Velasquez
 CONHI - DNP
 602/496-0739
 Donna.Velasquez@asu.edu

Dear Donna Velasquez:

On 11/23/2015 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Perceived Social Support and Quality of Life among Clients Participating in Cancer Support Services.
Investigator:	Donna Velasquez
IRB ID:	STUDY00003412
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> - survey part 3-The Flanagan Quality of Life Scale , Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); - survey part 1-Demographics, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); - Recruitment card, Category: Recruitment materials/advertisements /verbal scripts/phone scripts; - Thank you page- Online version only, Category: Participant materials (specific directions for them); - Severance_HRP 502-c consent short form, Category: Consent Form; - Thank you page- paper version only, Category: Participant materials (specific directions for them); - survey part 2-Multidimensional Scale of Perceived Social Support scale, Category: Measures (Survey questions/Interview questions /interview guides/focus

	<ul style="list-style-type: none"> group questions); - Protocol, Category: IRB Protocol;
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The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 11/23/2015.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc: Jennifer Severance

Appendix K

Table 3
Participant Demographics

Characteristics	n	(%)
Respondent		
Person with cancer	41	(87.2)
Supporter	6	(12.8)
Age Group (years)		
18-24	0	0
25-39	3	(6.3)
40-55	11	(22.9)
56-69	23	(47.9)
70+	11	(22.9)
Sex		
Male	11	(23.4)
Female	36	(76.6)
Race		
White	43	(93.5)
African American	1	(2.2)
Asian	2	(4.3)
Hispanic	5*	(10.6)*
Employment		
Retired	21	(43.8)
Working full time	8	(16.7)
Part time	6	(12.5)
Long term disability	5	(10.4)
Other (Unemployed, student, homemaker)	5	(10.4)
Self employed	3	(6.3)
Marital status		
Single	7	(14.6)
Long term live in partnership	3	(6.3)
First marriage	18	(37.5)
Remarried	9	(18.8)
Divorced	9	(18.8)
Widowed	2	(4.2)
Veteran	8	(16.7)
Education		
High School or less	2	(4.2)
Some college	11	(22.9)
2 yr college	8	(16.7)
4 yr college	11	(22.9)

Masters/Doctorate 16 (33.3)

Note. Using chi-squared analysis, we compared the sample to the previous local and national survey demographics
* $p < .05$

Table 4

Characteristics of persons with cancer (n=41)	n	(%)
Cancer type		
Female organs only (including BRCA)	14	(29.2)
Blood CAs	8	(16.7)
Gut CAs	4	(8.3)
Lung CAs	4	(8.3)
Male organs only	3	(6.3)
Other (skin, vocal, endocrine)	3	(6.3)
Declined to answer	6	
Cancer stage		
0-II: limited local spread	7	(17.9)
III: regional spread	6	(15.4)
IV: metastasized	6	(15.4)
Remission	11	(28.2)
Survivor	6	(15.4)
Reoccurrence	17	(35.4)
Second cancer	6	(12.5)

Note. Using chi-squared analysis, we compared the sample to the previous local and national survey demographics

* $p < .05$

Table 5

Instrument Mean (SD) Scores

Instrument	Mean	(SD)
QOL	83.7	(12.1)
MSPSS significant other	5.4	(1.7)
MSPSS family	5.1	(1.6)
MSPSS friends	5.3	(1.3)
MSPSS overall	5.2	(1.4)

Table 6

Summary of correlations, Means and Standard Deviations for Scores on the QOL, MSPSS, and MSPSS subscales

Measures	Mean	SD	1
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1. QOL	83.7	12.1	—
2. MSPSS overall	5.4	1.7	.458**
3. MSPSS significant other	5.1	1.6	.427**
4. MSPSS family	5.3	1.3	.360*
5. MSPSS friend	5.2	1.4	.435**

*p<.05, **p<.01, ***p<.001

Table 7

Correlations between instruments and number of different program used and frequency of attendance (n=41)

Measures	All programs		Support		Educational		Healthy activities		Social events	
	#	Freq.	#	Freq.	#	Freq.	#	Freq.	#	Freq.
QOL	.032	.116	.159	.116	-.083	-.022	-.018	.127	-.131	.002
MSPSS overall	.057	.109	.117	.109	.020	-.136	-.065	.125	-.139	-.102
MSPSS significant other	.076	.139	.103	.139	.050	-.137	-.012	.120	-.129	-.185
MSPSS family	.028	-.007	.019	-.007	.076	-.056	-.127	.123	-.022	.037
MSPSS friend	.057	.109	.117	.109	.020	-.136	-.064	.125	-.139	-.102

Note. Alpha set at < .05. All were found to be non-significant

Table 8

Correlations between perceived Health Control and program numbers, frequencies, and instruments

Instruments	Coefficient	n	p
MSPSS SO	.286	44	.060
MSPSS Family	.302*	44	.047*
MSPSS Friend	.305*	45	.042*
MSPSS Overall	.314*	44	.038*
QOL	.095	44	.539
Attend # support programs	.055	46	.717
Attend # healthy activities	.393**	46	.007**
Total # different programs	.326	46	.027
Frequency of healthy activities	.309*	46	.037*

Note. *p< .05, **p< .01. MSPSS = multidimensional scale perceived social support; SO = significant other; QOL= Quality of life score; # = number of different programs

Statistics Continued.

Table 9

Participant Reported Program Type attendance frequency within 2015

Program types	Reported Frequencies n (%)						Average Number of Agency programs		
	Never	Rarely	Less than once a month	1-2 times a month	About once a week	2-3 times a week	Days program avail. Per month	Individual programs	Program sessions per month
Support Services	19 (40)	11 (23)	5 (10)	4 (8)	8 (17)	1 (2)	20	7	31
Education	16 (33)	17 (35)	13 (27)	13 (27)	1 (2)*	1(2)*	3	5	3
Health Activities	27 (56)	7 (15)	3 (6)	5 (10)	5 (10)	1 (2)	16	14	36
Social Events	22 (46)	11 (23)	9 (19)	4 (8)	1 (2)	1 (2)*	5	7	5

* Not possible to attend the program types at the frequencies reported due to limited program availability; concluding participant memory of program attendance was unreliable.

Appendix L

Budget

Table 10

Budget outline: compared original cost to real expenses of this project

Item	Original cost	Cost for this project	Reason
SurveyMoz premium plan	\$300/year	\$0/year	Free membership for non-profits and educational institutes
Instrument use	\$0	\$0	Public domain scales
Printing Recruitment flyers Print paper surveys	\$45 through Vistaprint	\$ 80	Time restrictions and last minute changes did not allow for online orders
Locked ballot box	\$35 through Amazon	\$35	
IBM SPSS Statistics Professional v23	\$5,240/year	\$0/year	Grand student access, Licensed through ASU
Total	\$542/month	\$115	
Total for length of this project (4 months)	\$1892	\$115	Non-profit organization and doctorate of nursing practice student