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DEVELOPING A PEER CANCER SUPPORT GROUP EVALUATION

by

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A Capstone Project submitted in partial fulfillment of the requirement for the
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Executive Summary

This paper discusses how an evaluation was done on a peer cancer support group, Cancer Awareness Resource and Education (CARE). The peer cancer support group, CARE, is the only cancer support group provided at Zuckerberg San Francisco General Hospital and Trauma Center (ZSFG), San Francisco City and County's safety-net hospital. ZSFG serves a large underserved population such as those who are low-income, racial and ethnic minorities, and struggling with a medical condition. Evaluation is pertinent to understanding the efficacy of the program and to gaining support for the program's continual existence.

The evaluation included in-depth interviews with CARE participants to understand what is most valued and gained from participating in the program. Social support was a common theme that emerged in the analysis of the interviews, so pre-survey and post-survey were created to measure perceived social support and to take inventory of health-related benefits from participating in CARE. Due to the timing of the fieldwork, data from the post survey has not yet been collected, but the method of creating the evaluation, the in-depth interview findings, and the pre-survey findings are reported. Results from this project will be provided to CARE management to improve programming of CARE and to substantiate the continual support for the CARE program.

This paper recommends evaluation methods and tools to evaluate CARE's efficacy. In-depth interviews and short, simply worded in-session paper surveys examining perceived social support are recommended for CARE. This paper also recommends further research and advancements toward creating best practices for peer cancer support group evaluations. To improve peer support group evaluation methods and tools, all stakeholders especially cancer survivor participants need to be involved.

Abstract

Introduction: For many years, health care organizations have offered peer cancer support groups to cancer survivors, but peer cancer support group evaluation is not standardized. Without a clear and consistent evaluation, it may be difficult to understand the efficacy of and gain support for peer cancer support groups. In this paper, I discuss how an evaluation was created for a peer cancer support group called Cancer Awareness Resource and Education (CARE).

Methods: In-depth interviews with CARE participants were conducted and pre-survey and a post-survey were developed. The in-depth interviews included a convenience sample of eight individuals, two individuals from the following ethnic groups: African/African American, Asian/Pacific Islander, Caucasian, and Latino/Chicano. A pre-survey was also piloted on 25 CARE participants during a seminar.

Results: Social support was highly valued by CARE participants, with interviewees stating they came to CARE to meet other cancer survivors, they gain social support, and they continued to come to obtain additional social support. Since social support was commonly valued, a pre-survey and post-survey was created to measure social support.

Discussion: Conducting qualitative interviews to help create quantitative surveys seemed to be most effective for this project since no standardized peer cancer support evaluation method or tool exist. Social support seemed to be highly valued and leveraged in CARE, and should be the focus of future evaluation of cancer peer support groups.

Introduction

Cancer survivorship is an emerging area of care that has been driven by improved survival in the face of a historically deadly disease. Cancer forms when abnormal, old, or damaged cells divide without control, losing its functionality (NCI, 2015). Cancer can start almost anywhere in the body, can spread, and can lead to death (NCI, 2015). In the past cancer was regarded as a death sentence, but that has changed with cancer survival improving. It was estimated 13.7 million Americans were living with a history of cancer in 2012; that number is expected to be 18 million by 2020 (Siegel et al., 2012). There is a large population of people living with a history of cancer, and they are now tending to live longer. Since 1974, 5-year survival for the most common types of cancer combined has increased (Jemal, et al., 2017). The majority of cancer survivors, about 67%, were diagnosed 5 or more years ago, and 17% were diagnosed 20 or more years ago (American Cancer Society, 2016).

As cancer survival has improved, a definition of a cancer survivor has emerged. The National Coalition for Cancer Survivorship selected the words “cancer survivor” to convey two important messages: a message of hope for life after cancer, and a message to consider what happens beyond treatment (Ullman, 2014). Since there are more and more cancer survivors that need help beyond treatment, it seems pertinent to discuss cancer support that goes beyond medical intervention.

One way to provide support to cancer survivors is to offer a cancer support group. This paper will discuss first, how a cancer survivor peer support group was evaluated and second, will provide recommendations on method and tools for future evaluations and on program improvement.

Literature Review

Being a cancer survivor is at the forefront of my self-awareness. It enters into the conversations that I have with myself about what I want to do, how I want to spend money, how I want to spend time, my energy, all of that. Being a cancer survivor has added another dimension to my identity. I am a cancer survivor. — Dr. Mortimer Brown, 80, colorectal cancer survivor diagnosed (President’s Cancer Panel, 2004)

Evolution of Cancer Survivor Definition

Cancer survivorship is expanding and still being understood. Even the definition of a cancer

survivor has changed over time as cancer survival and cancer survivorship care have grown. When cancer was considered incurable, the term “survivors” was used to describe family members who experienced the loss of loved ones to cancer (Leigh, 1996). As cancer survival increased, physicians used the term “cancer survivor” to describe a person surviving cancer for five years or more after diagnosis or treatment (Leigh, 1996). The National Coalition for Cancer Survivorship (NCCS) does not use a five-year cancer survival condition. According to the NCCS, people are cancer survivors from the time they are diagnosed with cancer until the time they die (NCCS, 2014). The National Cancer Institute (NCI) has expanded the definition of cancer survivors to include people such as caregivers and family members who are affected by the cancer of loved ones (Aziz, 2002). For this paper, I will use the NCCS’s definition of cancer survivor. I will refer to people diagnosed with cancer as cancer survivors from the time of diagnosis on.

Cancer Incidence and Survival in the San Francisco Bay Area

Cancer is a prevalent disease not only in the United States, but also in the San Francisco Bay Area. In the San Francisco Bay Area, the five most common invasive cancers are: breast, prostate, lung and bronchus, colorectal, and melanoma cancer (Cancer Prevention Institute of California, 2016). Cancer kills more San Franciscans than any other cause (Hiatt & Ashworth, 2016). From 2009-2013, San Francisco cancer incidence rate has been 420.9 per 100,000 people (San Francisco Health Improvement Partnership, 2016a). From 2012-2014, San Francisco all cancer mortality rate has been 135.5 per 100,000 people, a decrease from 151.2 per 100,000 in 2009-2011 (San Francisco Health Improvement Partnership, 2016b). Fortunately, mortality rates in San Francisco have trended downward since 2009 (San Francisco Health Improvement Partnership, 2016b). There is a decrease in mortality and an increase in cancer survivors in San Francisco. According to Surveillance Epidemiology and End Results, NCI’s cancer registry of several states and two major metropolitan areas including San-Francisco-Oakland, there is an upward trend in the number of cancer survivors in the San Francisco Bay Area (Parry, Kent, Mariotto, Alfano, & Rowland, 2011). Given that the cancer survivor population is

growing in San Francisco, there is a high need to focus on cancer survivorship.

Physical Effects

People with cancer can improve their survival with diagnosis and treatment, but there are subsequent physical side effects from these interventions. Most cancers are given a diagnosis and stage (Cancer Research UK, 2014a). There are generally four stages: stage I includes small primary tumors that have not spread to other organs; Stage II and III include larger or more extensive primary tumors with or without cancer in nearby organs; Stage IV includes cancer that has spread from where it originated to other organs (Cancer Research UK, 2014b). Medical interventions are generally determined by type and stage of cancer, possible side effects, patient preferences, and overall patient health (Blinman, King, Norman, Viney, & Stockler, 2012). Some common cancer treatments are surgery, chemotherapy, and radiation. Undergoing cancer treatments may be difficult depending on the factors stated above because there are a variety of subsequent side effects. According to the National Cancer Institute, there are numerous common physical side effects from cancer treatment are anemia, appetite loss, bleeding and bruising, constipation, delirium, diarrhea, edema, fatigue, hair loss, infection and neutropenia, lymphedema, memory or concentration problems, mouth and throat problems, nausea and vomiting, nerve problems, pain, sexual and fertility problems, skin and nail change, sleep problems, and urinary and bladder problems.

Emotional Effects

In addition to physical side effects, studies have shown serious emotional effects from having cancer. According to the American Cancer Society, most people faced with cancer experience some degree of depression, anxiety, fear, or distress. Prevalence is estimated to be between 10% and 25% for major depressive disorder (Pirl, 2004). Diagnosable anxiety disorders are estimated to be 10%-30% in cancer survivors (Greer et al., 2011). Distresses can span from before to even after cancer treatment. A study found that 51% of newly diagnosed lung cancer patients reported clinically significant distress on the Distress Thermometer (Steinberg et al., 2009). Another study found that the prevalence rate of breast

cancer-related Post Traumatic Stress Disorder is 6% even after treatment (Andrykowski, Cordova, Studts, & Miller, 1998).

Understanding the Multiple Effects of Cancer

Cancer survivors are dealing with multiple serious issues. Testimony from cancer survivors can better describe the depth of distress. Cancer survivors provided testimonies to the President of the United States of America through the President's Cancer Panel to explain the immense challenges cancer survivors face. In the following testimony, a cancer survivor described her anxiety of cancer recurrence and cancer treatment complications even many years after treatment.

My concerns as a survivor have evolved the farther away I have gotten from treatment... During my treatment and for several years after...my primary concern was recurrence... [Now] I worry about secondary cancers...and problems due to my [treatment]... I am in premature menopause because of the high doses of chemotherapy I received, so I worry about osteoporosis, sexuality, cardiac problems, and yes, even wrinkles. —Karen Dyer, 24, rhabdomyosarcoma survivor (President's Cancer Panel, 2004)

Cancer survivors experience a considerable amount of physical and emotional issues relating to cancer that begins from the time of diagnosis on. There are even issues that are beyond physical and emotional problems that complicate multiple parts of life and overall quality of life. The follow testimony is from a cancer survivor who is a mother and head of household.

[My husband] decided to move on. I had three young children depending on me. There was no room for me to be sick but I didn't have a choice... The 'repo' man came to take our car... [My kids] did odd jobs so that I could have the gas money to go back and forth [to treatment]... I became so depressed until I just didn't want to live anymore... [My kids said,] 'You can't give up. You have come so far... —Barbara Young, 50, breast and stomach cancer survivor, diagnosed at ages 34, 41, and 44 (President's Cancer Panel, 2004)

In the case of this cancer survivor, cancer also affected her family relationships, her financial stability, and even her identity as a mother and provider to her children. Cancer can affect a person's overall quality of life. According to the Centers of Disease Control and Prevention, the diagnosis of cancer is a threat to a cancer survivor's physical, psychological, social, spiritual, and economic wellbeing (Centers of Disease Control and Prevention, 2014). The impact cancer has on cancer survivors' overall wellbeing and quality of life can make cancer survivors very vulnerable.

Assisting Cancer Survivors with Support Groups

The unique vulnerabilities of cancer survivors suggest they may need several avenues of help. One avenue of assistance can be through cancer support groups. There are several types of cancer support groups. Cancer support groups may be convened in person, on the web, or on the telephone. Cancer support groups can be lead by medical professionals, a fellow cancer survivor described in this paper as a peer, or another type of person. For this project, I will focus on in-person peer cancer support groups. Cancer support groups can serve various purposes depending on the design, vision, mission, and goals of the program.

The Purpose of Cancer Support Group Evaluations

Cancer support group evaluations can be a good way to know how cancer survivors are faring in various aspects of life, and to know how cancer support groups are helping its cancer survivor members. Evaluations such as process and outcome evaluations on cancer support group participants can measure respectively how cancer survivors are improving while participating in the cancer support group and how cancer survivors are doing overall. Cancer support group evaluations can also be an ideal way to obtain cancer survivorship information by providing institutions a large and convenient sample of cancer survivors.

Evaluation Methods

There are many ways evaluations on can be done on cancer support groups. Three main methods of evaluations exist: qualitative, quantitative, and mixed-methods that use both quantitative and qualitative methods. Quantitative data involves numbers while qualitative data involves words, videos, and pictures. Quantitative data usually is collected from a larger sample of people compared to qualitative data, but qualitative data captures people's voices and detailed explanations (Lee, 2013). Both qualitative and quantitative data are valuable, but decision makers tend to like quantitative data (Lee, 2013). According to a systematic review on peer cancer support groups, there is a lack of guidance on evaluations; therefore, it may be unclear how to conduct a rigorous evaluation (Campbell, Phaneuf,

Deane, & 2004).

Quantitative Survey Tools

There are several quantitative survey tools used by cancer support programs like those presented in Table 1. The survey tools in Table 1 were selected for presentation because they are commonly used to measure multiple aspects of life. According a national survey on patient navigation and cancer survivorship programs, the National Cancer Network Distress thermometer is the most common assessment tool used in about 50% of patient navigation and cancer survivorship programs (George Washington Cancer Institute, 2013). An authority in cancer, National Comprehensive Cancer Network, provides the National Comprehensive Cancer Network Distress Thermometer to help cancer survivors describe the distress they are feeling. Though this is popular, it only allows cancer survivors to provide one overall score to describe their distress. It is not granular enough to pick smaller changes and it may not be suitable for a pretest and posttest evaluation design. Functional Assessment of Cancer Therapy – General(FACT-G) is a survey used in about 8% of cancer patient navigation and cancer survivorship programs (George Washington Cancer Institute, 2013). FACT-G evaluates health-related quality of life

Table 1	
Example Survey Tools	
Survey Tools	Source
National Comprehensive Cancer Network Distress Thermometer	Jacobsen, et. al., 2005
FACT-G	Winstead-Fry & Schultz, 1997
EORTC Quality of Life Questionnaire C30	Aaronson, et al, 1993
Edmonton Symptom Assessment System (ESAS)	Bruera, Kuehn, Miller, Selmsler, & Macmillan, 1991
SF-12 Health survey	Ware, Kosinski, & Keller, 1996
Quality of Life Patient/Cancer Survivor Version (QOL-CSV)	Ferrell, B., et al, 2012

for general cancer patients. It has several Likert scale questions and is designed to pick up more granular changes, but it does not measure spiritual and financial wellbeing. Like FACT-G, other surveys ask several questions with a Likert scale, but may not cover all five dimensions of wellbeing affected by cancer as described by the CDC. The only survey listed that uses a Likert scale and measures all five dimensions of wellbeing is the Quality of Life Patient/Cancer Survivor Version (Ferrell, B., Hassey-Dow, K., Grant, M. et al, 2012). Unfortunately, literature has not found it to be a common survey tool used to evaluate cancer support groups.

Lack of Standardized Qualitative Survey Tools

Though there are many survey tools to assess cancer support programs that capture various aspects of cancer survivorship, no one survey clearly prevails, is deemed superior over all others, and is commonly used. The National Cancer Institute's measures database currently lists 192 survey tools relating to cancer survivorship. In the database the tools can be reviewed and rated up to five stars, but only 4 survey tools currently have five stars with only one to four reviewers. This may indicate that there are many survey tools and little consensus on what survey tool is best. The Malin, Sayers, and Jefford 2011 study on quality of cancer care corroborates this by concluding that there is currently no set of validated survey tools specific to cancer survivorship. In addition to this, the American Society of Clinical Oncology states that there is a lack of guidance for assessment and management for long-term cancer survivorship support, and suggests that a standardized outcome measure is needed. A systematic review on the efficacy of cancer peer support groups specifically states, "This field would also benefit from more consistent use of standard outcome measures" (Campbell, Phaneuf, Deane, & 2004). Another systematic view on cancer support groups finds little research specifically on the effectiveness of peer support groups, and urges for more studies (Hoey, Ieropoli, White, Jefford, 2008). Currently, there seems to be no standard way to precisely evaluate how cancer survivors are doing. To date, there seems to be no standardized tools to rigorously and accurately assess the efficacy of peer cancer support groups.

CARE Agency Profile

The Cancer Awareness, Resources, and Education (CARE) provides a peer cancer support group in the form of 9-12 weeks seminar series to Zuckerberg San Francisco Hospital and Trauma Center (ZSFG formally known as San Francisco General Hospital or SFGH) patients. Since ZSFG is a safety-net hospital, it serves a large underserved community. CARE provides seminars series in three languages: English, Spanish, and Cantonese. CARE staff also supports their participants by making home calls, reminders, and giving additional help as needed. CARE is also provided at no cost to the participant.

History

In 2001 the SF Foundation approached the San Francisco General Hospital (SFGH) Foundation with a donation from a donor interested in establishing programs for low-income people with cancer. The donation was generously given to CARE by a former SFGH cancer patient. That year the executive director of the SFGH Foundation appointed the director of patient education to develop a program. Since October of 2002, the CARE program has provided cancer support to thousands of medically underserved cancer patients. The CARE support group model is based on a tailored educational program with a loving and supportive atmosphere. The English and Spanish CARE seminar series began in October 2002. The Chinese seminar series began in 2005. Currently, CARE is a program within and overseen by Community Wellness Program. The Community Wellness Program has its own center on the second floor of the hospital in the Community Wellness Center across from the hospital cafeteria. Many patient walk by this room. The Community Wellness Center houses various programs that promote health and wellness.

The following CARE vision, mission, and objectives are presented and edited for clarity. This is not the initial vision, mission, and goals created by the original CARE program planning team.

Vision

All cancer survivors thrive with hope and purpose throughout their cancer journey at ZSFG.

Mission

To deliver humanistic, culturally, and linguistically appropriate health education and psychosocial support.

Goals

- Build a cohesive and expanding cancer survivor community within ZSFG.
- Encourage personal awareness, so individuals can work toward fulfilling their health and wellness needs in order to enhance their quality of life.
- Improve relationships and communication between cancer survivors and health professionals

Funding

CARE was awarded the California Pacific Excellence in Patient Education Award and the AMA Innovative Approaches to Patient Centered Communication Award in 2002. In 2004, Hematology/Oncology division at SFGH along with Avon Foundation monies supported CARE staff. Due to various reasons, CARE funding since the initial support has been tenuous. Currently CARE is funded by a grant from AVON Foundation, and the San Francisco Department of Public Health and ZSFG. The CARE Coordinator works 40% of full-time equivalent for CARE. The CARE Director also works 40% of full-time equivalent for CARE. Donations for CARE are currently diminishing, so CARE is in need of extra funding.

Service offerings

CARE provides support groups once a week for a 9-12 week long three times annually. The topics vary, but all are related to cancer. CARE is provided in the three major languages spoken by patients: English, Spanish, and Cantonese. Each language has its own seminar series. CARE is designed for low-income participants, but participants can come from a range of socioeconomic statuses. At the CARE seminars, food is provided, peer discussion is encouraged, and educational presentations are given. English and Spanish CARE are conducted similarly. Both groups beginning with a one hour to

one and a half hour check in process that allows attendees to introduce themselves and their cancer related updates to the group. The next thirty minutes to an hour, an expert presents. Lastly, a facilitator or volunteer participant gives closing remarks. Chinese CARE runs differently and only provides a lengthy presentation. At the end of each CARE seminar, a healthy dinner is provided to the participants to take home to encourage healthier eating. CARE also makes weekly calls to established and prospective participants to see how they are doing and reminds them to come to CARE. If any CARE participant is in extreme need they are typically referred to the CARE director. The CARE director has health education experience, so she can provide individualized education or help the participant find the appropriate resources at ZSFG.

Target population/Client mix

CARE accepts any cancer survivor that shows up at and registers with the Community Wellness Center at ZSFG; however, CARE has a relationship with various ZSFG departments such as: Hematology/Oncology, Breast Clinic, Physical Therapy, Chemotherapy, Women's Clinic, Family Practice, and Social Work. CARE has a closer history with Hematology/Oncology. Compared to the General Population of cancer patients ZSFG, Oncology Patients tend to be ≥ 10 yrs younger at diagnosis (52 years old vs. 63 years old) and present at more advanced stages (10% v. 5%). They also tend to have poorer survival outcomes (60% 1-year mortality v. 30% 1-year mortality) and up to 50% do not speak English.

Providers from ZSFG clinical departments can refer patients to CARE, or cancer survivors from the community can simply go to CARE. CARE accepts all attendees, but since CARE participants usually come from ZSFG clinics, they tend to be lower-income, younger, have more advanced cancer, and have fewer English language skills. CARE participants are of all racial and ethnic backgrounds. Many CARE participants face challenges related to poverty, unstable housing, immigration status, language barriers, literacy difficulties, substance use, and/or mental health issues. They may lack computer literacy, access to the Internet, and/or connections to helpful people/resources. CARE

participants may feel mistrust of the medical establishment and related institutions. They also may be less disposed to asking health providers questions regarding care or treatment plan.

Culture

From experience, the support group has a loving, supportive, and uplifting culture. The participants seem to enjoy being around peers who experienced a similar fight against cancer. Participants find comfort with their peers' honesty and encourage a culture of honesty and humility. Facilitators encourage curiosity and are willing to slow the workshop to keep discussion going. The participants enjoy CARE, but may feel at odds with ZSFG since ZSFG may not meet all of their needs and desires given that ZSFG is a safety-net with limited resources and overstretched staff. CARE participants have a mixture of appreciation and honest criticism of resources at ZSFG.

Agency Needs and Challenges

CARE needed evaluation of the program for two main purposes. The primary purpose is to learn from participants how we can improve the program to meet their needs. The secondary purpose was to do an evaluation on the efficacy of CARE to provide justification of support to current and prospective stakeholders. CARE's original goals were very broad and a formal program evaluation on the efficacy of CARE has not been planned or conducted. Without best practices on evaluation CARE needed input from researchers to conduct the evaluation.

An analysis was done to identify strengths, weaknesses, opportunities, and threats called a SWOT analysis. A SWOT analysis is located in Appendix A. After doing the SWOT analysis, it is obvious that lacking funds provides a significant weakness and threat because it can lead to CARE dying. To obtain funds, it seems as if CARE should be specific on what it has achieved and how it is achieving that, so CARE can substantiate receiving financial support. The strengths are that CARE already has many presenter and community organization relationships, and has a loyal participant following. CARE can use those professional relationships to help get funding. CARE can use its

loyal participant followings to get feedback and support in defining CARE, evaluating CARE, and improving the program.

Methods

Evaluation Methods

There are two major research questions for this project: first is what do CARE participants most value about CARE, second is how efficacious is CARE in providing that value. The research design included in-depth interviews used to address the first major question, and a pilot pre-survey and post survey used to address the second major question. The pre-survey and post-survey were chosen because there is a start and end time within each series, so there is a chance to show changes before and after participating, and surveys can yield numerical results necessary to easily depict the efficacy of the program to stakeholders. In-depth interviews were chosen because cancer survivorship is complicated and the original goals of CARE were too broad to identify specific constructs that should be measure in a quantitative survey. The data from the in-depth interviews was used to develop the survey. This method was used to ensure what is evaluated in the survey matches the needs and goals of its participants as suggested by Gottlieb & Wachala's 2007 systematic review on cancer support groups. It's important to allow participants to define goals and outcome of the program because it otherwise may not be wanted or even obtainable by participating in a support group (Gottlieb & Wachala, 2007).

In-depth interviews

The in-depth interviews were conducted with eight CARE participants, a male and female from the following racial/ethnic groups: African American/African, Asian/Pacific Islander, Caucasian, and Latino/Chicano. This was a convenient sample of people who were approached by me after a few CARE sessions and accepted my invitation to be interviewed. I went to several CARE sessions and participated in group activities, so they would get familiar with me. Over a few

weeks from May to July 2017, I introduced myself to several participants as a student researcher who wanted to hear about their experiences in confidence. For those who accepted the invitation to be interviewed, I scheduled interviews at a convenient time in a private room in the hospital. The interviews were audio recorded and conducted using an interview guide and interview data collection form. The interview lasted between 60 to 90 minutes. The names of the interviewee were not collected and a unique record number was assigned to each interviewee instead. The unique record number kept confidentiality and reduced bias during analysis.

The interview guide and collection form were produced with input from CARE staff, a CARE participant, and two researchers both with qualitative research experience. The questions are open-ended questions. Before each interview, a script was read to each participant that asked for permission to do an interview, audio record it, and use the data for a CARE evaluation project. Each person interviewed was told that the interview can be ended at any time and any questions can be skipped. The interview guide and data collection form are in Appendix C. The first part of the interview in section I and II is designed to capture what participants value about CARE by asking question around why people came to CARE, why they returned to CARE, and what did they gain from CARE. CARE staff suggested question about CARE's vision and competing resources. The third section asked participants what they think the vision of CARE should be. The fourth section asked about how to best get feedback. The fifth was used to identify any competing programs. The interview was then transcribed and key testimonies describing themes of the interviews were extracted and reported.

Survey

The survey was designed after conducting interviews with input with CARE staff, a CARE participant, and two researchers. Due to scheduling challenges, the pre-survey was piloted on July 11, 2017 the second CARE session of the summer 2017 series to whoever was present at the

Community Wellness Center. Due to unaligned timing of the internship and summer 2017 CARE series the post survey was not done. During the CARE seminar on July 11, 2017 the facilitator announced at the beginning of the session that the pre-survey would be piloted after introductions. Prior to passing out the surveys, I announced my name, and said my survey was designed to evaluate and improve CARE and that anyone was welcomed to do my survey if they liked. Volunteers then passed out the survey while CARE management was not present. Surveys and pens were offered to all who accepted it. After the survey was passed out, I let participant know they can ask me question or feedback before we moved on with the rest of the CARE session. Valuable feedback was then used to edit the survey included in Appendix C. Volunteer collected all the surveys after everyone was done. It took approximately 20 minutes for all the survey to be complete.

In the survey, it asks demographic information, type of cancer, cancer stage, and place in cancer care continuum need for CARE. The pre-survey asks for name, but this was only done by request of CARE staff, so CARE staff can identify if someone is in dire need. The name, however, was removed and a record number was provided before pooling data together and analyzing for this study. This was used to ensure confidentiality and reduce biases in analysis and reporting. Additionally, at the top of the survey it states that the survey is confidential, will be combined into a report for CARE improvement, and will not affect participants' participation in CARE. This statement is used to show there will be confidentiality, and to elicit a more honest response.

From interviews, social support seemed to be a theme, with all eight participants speaking about receiving support from other cancer survivors. Therefore, the survey used an adapted validated perceived social support survey tool with Cronbach's alpha of 0.88 (Li, Chen, & Popiel, 2015). The scoring for analysis method was also adapted for simplicity. To cross-reference the findings of the interviews, a question on the main reason for coming to CARE was added. It was

used to make sure peer support is relevant to the large non-interviewed group. Other information outside of the scope of the project was also collected by the request of CARE staff. Questions on when they learned about CARE was out of the scope, but was included to determine challenges in outreach. After the pre-survey was conducted, two CARE participants gave feedback mainly on the Likert scale wording, so the second pre-survey version and post-survey were modified based on this feedback. Only the pre-survey results are reported in this paper since the seminar series extends beyond the project deadline.

The post-survey is shown in appendix D. In addition to the components of the survey mentioned above, the post-survey asks participants to inventory the variety of benefits gained from participating in CARE. This inventory was added to attempt to quantify the number of people gaining certain health-related benefits. This component was important to add so that it can be used to substantiate support from stakeholders interested in health-related outcomes. The post-survey will be done the last day of the summer 2017 CARE series and will not be reported in this paper.

Results

In-depth Interview Findings

There were eight in-depth interviews each with a record number 001 to 008. Table 2 shows each record number's demographic information, cancer types and stage, and year diagnosed with the cancer. Male and females from African American/African, Asian/Pacific Islander, Caucasian, and Latino/Chicano racial/ethnic groups were interviewed. The average age of the interviewees was 59 years old. The ages ranged from 51 to 69 years old. Most were diagnosed in 2016. The earliest diagnosis was in 2006 and the latest was in 2016. Three out of eight had stage 4 cancer. Stage 1 and 2 as well as people without a stage were represented. Interviewees had a variety of diagnoses, but three had breast cancer and two had myeloma. Most had 1 type of cancer. One person has cancer in multiple organs.

Record number	Gender (M for male, F female)	Age	Race/Ethnicity	Cancer type, Stage	Year Diagnosed
001	M	52	Latino/Chicano	Myeloma, Unknown stage	2016
002	M	57	Caucasian	Colon, Stage 4	2016
003	F	53	Latino/Chicano	Lung, Stage 4	2016
004	F	69	Caucasian	Breast, Stage 2	2015
005	F	59	Asian/Pacific Islander	Stomach, Ovary, Breast, Stage 4	2006
006	M	69	African/African American, Caribbean	Chronic Lymphocyte Leukemia, No Stage provided	2009
007	M	60	Asian/Pacific Islander	Breast, Stage 1	2016
008	F	51	African/African American	Multiple Myeloma, No stage provided	2011

In the in-depth interviews we asked how best to get feedback from CARE participants; most people said in-session surveys were best with a minority of people suggesting direct feedback. Four out of eight said paper surveys fielded during CARE sessions works well. Three said they prefer to give direct feedback in person to CARE staff. One said he didn't feel comfortable giving feedback at all. A few suggested other survey designs. Two suggested having short surveys. One suggested having a survey online, so it can be completed anytime. Table 3 provides quotes showing preferences for giving

feedback to CARE staff about CARE performance. From the surveys, two points to keep in mind include length and time allotted to complete the surveys.

Main questions/ comment type	Quotes
<p>How would you like to give feedback to CARE?</p>	<p><i>“You have that exit survey, which is good since things are fresh in your mind, so if I had something to say I can use that form. I think a survey is more important than having a [comment] box, so everyone does it.” —57 year old Caucasian Male, Stage 4 Colon Cancer Survivor</i></p> <p><i>“Its okay. They have the survey, but they are rushing.”—59 year old Asian/Pacific Islander Female, Stage 4 Stomach, Breast, and Ovary Cancer Survivor</i></p> <p><i>“I like the one on one approach. I know I can talk to anybody there. I would like to come up to you...I know I have [the CARE manager’s] office number and I can call her. I haven’t called, but I have her number”—69 year old Caucasian Female Stage 2 Breast Cancer Survivor</i></p>
<p>Design of survey</p>	<p><i>“Do one of the survey things online with like 10 questions and say it take 5 minutes, so you know. Otherwise you can take a survey and its like oh my god, its so many questions.” —57 year old Caucasian Male, Stage 4 Colon Cancer Survivor</i></p>

There were several questions asked to determine what is most valued and gained from participating in CARE, including questions about why people joined CARE, what they feel is the best part of CARE, and what makes them return to CARE. All eight interviewees mentioned how important it was for them to gain social support from other cancer survivors in the CARE program. Some mentioned education as being important as well. Table 4 and Table 5 shows quotes presented thematically to illustrate what value CARE brings to its participants. Those interviewed talked about how important speaking to cancer survivors is to gaining things such as experiential knowledge of what is to come, hope, inspiration, acceptance of diagnosis, and emotional support. Participants felt these were things doctors couldn’t necessarily give, but peer cancer survivors from CARE could. Social

support from CARE seemed to drive people to have positive changes that could affect their health such as feeling less anxious, sleeping better, managing life better, and improving emotional wellbeing.

Table 4 In-Depth Interview Quotes Regarding the Value Gained From CARE	
Main questions/ comment type	Quotes
Why did you decide to join CARE?	<p><i>“My daughter she doesn’t get it. People don’t get it. My friends are like what do you mean you have cancer, you don’t have cancer, you’re a cancer survivor. But somewhere in my mind its still there. Did it all go away? No! I still have to take medicine. I still need to go to therapy. And my life in still in the drain. So, it’s still like I am going through it. I am still dealing with the pain relating to this, [cancer]... I thought it would be good to be around other [cancer survivors].”</i>—69 year old Caucasian Female, Stage 2 Breast Cancer survivor</p> <p><i>“When you are really sick you need someone to talk to because in your family, sometimes it is hard to discuss what your feeling is, but with others with the cancer its like they know what your are feeling.”</i>—59 year old Asian/Pacific Islander Female, Stage 4 Stomach, Ovary, and Breast Cancer Survivor.</p> <p><i>“My father was a psychologist, so I know how important these things are on a emotional level, on a educational level I know these support groups can be really important. Plus there are details only people going through these things can understand. And so that feels good. It feels nurturing to find people.”</i>—57 year old Caucasian Male, Stage 4 Colon Cancer Survivor</p>
What about CARE keeps you coming back?	<p><i>“I thought it would be good to be around other [cancer survivors] and it was. I am very private person, so it was special.”</i>—69 year old Caucasian Female, Stage 2 Breast Cancer Survivor</p> <p><i>“The people keep me coming back because people care. You get to know people and they are my friends now. You know we have this time every week. If you missed it and you are like damn I missed CARE. Its the camaraderie and everyone is having a good time.”</i>—51 year old African American Female, Multiple Myeloma</p>

The recurring theme of the in-depth interviews indicated that social support is vital to CARE and should be examined further. Participants stated they are coming to CARE for social support and information they cannot get from their physician, and that participants are returning to CARE because CARE has a caring, understanding environment with a sense of camaraderie and it can be fun. Participants believed they are getting the support that is good for the body and the soul, they are feeling

less anxious, sleeping better, managing their life better, and getting hope and emotional support. Social support may not only be key to understanding how efficacious CARE is, but it may indicate that other health promoting benefits being gained from participating. From the testimony it seems like social

Table 5	
In-Depth Interview Quotes Regarding the Value Gained From CARE	
Main questions/ comment type	Quotes
What have you gained from coming to CARE?	<p><i>“There are details only people going through these things can understand. And so that feels good. It feels nurturing to find people [other cancer survivors]...I think that type of support we have in CARE and that type of networking its good for the soul. What’s good for the soul is good for the body. Healthy mind, healthy body”.—57 year old Caucasian Male, Stage 4 Colon Cancer Survivor.</i></p> <p><i>“[CARE], it made me feel less anxious and that I am not alone. It’s a big thing because like I said my daughter and my friends don’t quite get it. I am feeling like someone gets].”—69 year old Caucasian Female, Stage 2 breast cancer survivor</i></p> <p><i>“I [benefitted from CARE] by accepting [my cancer]. I hear other people speaking about it and they are more sicker and they survive. They are my heroes. I cannot sleep because I no accepting, but now I accepting—I sleep a little bit more. Also the medicine helping me. When you are accepting why are you sick, you are accepting why you are tired, you accepting why [you have symptoms], you accepting that people look at you different.”— 53 year old Latina Female, Stage 4 lung cancer survivor</i></p> <p><i>“CARE got me to a point where I can manage my life again and give back and try to help people. There are a couple members in the group that I talk to when they first came in and there were people who talked to me when I first came in...There is a sense of commonality, comfort, and support that people have toward one another that they get for themselves.”—69 year old African American and Caribbean, Chronic Lymphocyte Leukemia</i></p> <p><i>“When you meet many people who are surviving. It gives you hope. It is probably the biggest thing I gotten from CARE is the hope [from other cancer survivors]. It has definitely affected me emotionally.”— 51 year old African American Female, Multiple Myeloma</i></p>

support may indicate small improvements in social wellbeing, emotional welling, physical wellbeing and more.

Pre-survey Interview Findings

There were 25 pre-surveys done with a few not being fully completed. Table 6 shows the demographic statistics for age, gender, race/ethnicity, and financial stability. The average age was about 62 with the youngest being 50 years old and the oldest being 79 years old. There were more females than males. The largest racial/ethnic group was Asian/Pacific Islanders followed by Caucasians and African/African Americans. Most who were surveyed are somewhat financially instable.

Table 6		
Pre-survey Demographic Information		
Age		
Average (Range)	62(50-79) years old	
Gender		
Percent (Number)	Male: 40%(10)	Female 60%(15)
Race/Ethnicity		
Percent (Number)	African/African American	17%(4)
	Asian/Pacific Islander	42%(10)
	Caucasian	29%(7)
	Latino/Chicano	8%(2)
	Other	4%(1)
Financial instability		
	Instable	12%(3)
	Somewhat instable	64%(16)
	Stable	24%(6)

Cancer types, stages, and places in cancer continuum and shown in Table 7 located in appendix E. Participants indicated they have single and multiples cancers. Stages 1 to 4 were represented and some did not indicate their stage or did not have a diagnosis with a stage. Stage 4 had the highest representation and Stage 1 had the lowest. There were ten different cancers represented with the most common being breast cancer, followed by chronic lymphocyte leukemia and lung cancer. People were in various places in the cancer care continuum, but the most common place in done with treatment for over a year with the second most common place being currently in treatment within the last 6 months.

Data on how familiar people were with CARE and how long they have attended was collected. Table 8 in appendix F shows how familiar participants are with CARE and how long they have been members of CARE. Most were CARE veterans meaning they were very familiar with CARE. The CARE veterans had an average of 7 years participation in CARE and ranged from 2 to 11 years in

CARE. A few said they were new to CARE and on average spent only 1 month in CARE. The average length of membership was 3.5 years with the longest being 11 years, and the shortest being brand new to CARE. This information may be valuable to examine the dosage effect.

Data on perceived social support from an adapted perceived social support survey tool included in the pre-survey was collected and converted into quantifiable data. The social support survey tool had five items scored by Likert scale using a converted numerical score -2 to 2, with -2 being the lowest score and 2 being the high score for each item. In total the lowest possible score was -10 indicating the lowest perceived social support and the highest possible score was 10 indicating the highest perceived social support. From the surveys, the average perceived social support score was about 5, with the highest being 10 and the lowest being -5.

Table 9		
Reasons participants joined CARE		
Main reason for joining CARE		
Percent (Number)	To talk with other cancer survivors who understand	70%(19)
	To get emotional support	63%(17)
	To learn about cancer from presenters	63%(17)
	To get connected to resources	30%(8)
	To get a healthy dinner	33%(9)
	Other	11%(3)

There were a variety of reasons people joined CARE. Most people selected more than 1 reason.

Table 9 shows the reasons, and the percent and number of participants who selected each reason. The most common reason people came was to talk to other cancer survivors who understand followed by to get emotional support and learn about cancer from presenters. A minority of participants joined CARE to get connected with resources and to get a healthy dinner. A few selected other and wrote something about sharing and inspiring others battling cancer. The data showed that not only was social support important to the interviewees, but also to the majority of people who were surveyed. This aligns with what was seen in the in-depth interview.

Implications for practice

The project goal was to evaluate CARE, a peer cancer support group. The project was necessary since CARE staff needed to understand the efficacy of the program in order to substantiate stakeholder support and to improve the CARE program. In order to evaluate it, in-depth interviews were conducted to discern value CARE provides to its participants. From the interviews social support seemed to provide the most value as it was most commonly mentioned as the reason people came to CARE and returned to CARE, and it was what participants gained from CARE. This led to us using a perceived peer survey tool in our quantitative survey. By evaluating perceived social support, it can help CARE staff understand how much social support CARE participants gained. The survey may also assist CARE staff in improving the program by helping them decide to further focus on social support.

The in-depth interviews were key to conducting this evaluation because it brought CARE participants' voices into the discussion around how to determine CARE's performance. Understanding the efficacy of CARE from the lenses of participants aligns both program and participants goals. It also led to the design of the survey. I recommend collecting qualitative data like the quotes collected from the in-depth interviews because it gives detail explanations on what participants want from the peer support group, and why they want it and why it is important.

The quantitative surveys were key in accomplishing the project goal because it corroborates what was heard in the in-depth interviews, and it provides information CARE staff need. Both the in-depth interviews and surveys indicated that social support is desired. Social support was the main reason why people participate in CARE. Since particular stakeholders want quantitative data, the quantitative survey results meet CARE staff needs. The quantitative data can address a major threat to CARE of not having quantitative data to defend the support of the program, and possibly not being able to obtain the support of stakeholders and expanding funding sources. The quantitative data can be used to justify and improve new and existing stakeholder support.

There are several reasons why qualitative and quantitative data were used to evaluate this program. The reasons include complexity of cancer survivorship, diversity of support needed, and board goal of the CARE program. This set of challenges made it hard for a researcher and a community program designer to determine the type of evaluation needed to assess program performance and participant needs. If other peer support programs have a similar challenges as CARE, I recommend collecting qualitative and quantitative data similar to what is shown in this paper. In-depth interviews informing the quantitative survey development seemed to work well for the project goal and the CARE staff needs.

Discussion

Developing the evaluation of CARE was not a simple task. The program and lack of literature provided challenges. The program provided challenges since the original vision, mission, and objectives were broad and needed some revision. They could not be used to specify what constructs need to be evaluated. The lack of literature provided challenges since limited standard methods and survey tools to evaluate cancer support groups were identified. No best practices on evaluating peer cancer support groups such as methods and tools were known. To address this challenge, in-depth interviews were conducted to help inform the survey development. Questions from the in-depth interview were designed to determine what CARE participants' value the most from attending CARE. Social support was a recurring theme in all the in-depth interviews, so the perceived social support construct was used to make quantitative surveys that could evaluate CARE's performance and give clues to what needs improving. Social support seems like a promising construct because the surveys showed that participants' main reason for joining CARE indeed was to talk with others. The social support construct is also promising because CARE participants testimonies show the variety of benefits gained from social support that range from social benefits, emotional benefits, physical benefits, and to even more. There even can be a possibility these benefits are health and wellbeing related.

Challenges in Evaluating Peer Cancer Support Groups in the Literature

The challenges I faced and my findings were also seen in the literature. In the Campbell, Phaneuf, & Deane, 2004 systematic review, the authors discussed the challenges researchers had in evaluating peer support groups. Campbell, Phaneuf, & Deane's 2004 review discussed how studies lacked a thorough and clear description of the program, and had methodical flaws amongst other challenges. A different systematic review on cancer support groups also discussed the methodical challenges, but went on to suggest that methodical problems could be due to the inappropriate outcome measures used (Hoey, Ieropoli, White, Jefford, 2008). Another systematic review summarized evaluation issues in three parts that link the methodical flaws with program plan flaws (Gottlieb & Wachala, 2007). The first is that the cancer support group planner needs to be clear as to whether the group is supposed to cause the outcome of interest or be the stepping-stone toward the outcome (Gottlieb & Wachala, 2007). The second is that the program planners rarely consult participants in determining the desired outcome, which could result in nonmatching desired outcome (Gottlieb & Wachala, 2007). The third is attrition and performance may be low if program planners don't match their outcome goals and measures with goals desired and expected by the participants (Gottlieb & Wachala, 2007). The challenges reported in the literature regarding program design and evaluation design is similar to challenges seen in CARE prior to this project.

Addressing Challenges

I addressed the evaluation design challenges stated above by seeking the CARE participants' input. By interviewing them, I allowed them to tell me in their own words what mattered to them and what value CARE brought to their lives. Social support was what they were after, needed, and what they gained from CARE. The perceived social support construct was actually different from what I and CARE staff were initially thinking of measuring. Initially, we were thinking of measuring health-related quality of life, but there were issues with using that measure since a lot more than the cancer support group affects quality of life. The reason why we were attracted to health-related quality of life construct

was because we were formally trained in health and were in a hospital setting, so we felt hospital stakeholder would be most satisfied with this construct. Health-related quality of life was initially thought of since the ultimate goal of the hospital is to improve the health of the community. However, if quality of life were selected the change between the pre-survey and post survey may report no or negative change, not accurately reflecting the efficacy of the program. There might be no or negative change in health-related quality of life if other factors such as disease progress or financial burden happens to negatively affect CARE's participants during the study. Given our population is vulnerable, there is a high chance this can happen. A poor selection of construct to measure can lead to poor reporting of efficacy and lost support for CARE, a possible result not necessarily warranted.

Instead of choosing health-related quality of life, we decided to allow participants to choose the construct by telling us what they valued and gained from CARE. This approach solves some of the challenges regarding disconnect between participants goals and program planner goals. The social support construct is a much more appropriate measure because it aligns the desired outcomes of the CARE peer cancer support group as well as the participants. From qualitative evidence, it seems like social support is more obtainable with CARE, and it accurately describes what participants get from CARE. Our methods solves challenges stated in Gottlieb & Wachala's 2007 review because we know social support can be a step toward health-related benefits as described above, social support is something both us and participants are interested in, and this alignment of interest can improve programing in the eyes of both the program planner and participants.

Limitations

There are several limitations in conducting a full rigorous evaluation of CARE. A major limitation had to do with the timing. The projected needed to be done within the period of an internship, but that did not match up with the CARE seminar series; therefore, only the in-depth interviews and pre-survey was done. The post survey will be conducted at the end of the CARE summer seminar series in late August 2017. Another timing issue had to do with when the pre-survey was conducted. The pre-

survey was not conducted the first day of the summer seminar series due to prior commitments CARE staff made to presenters. However, if the pre-survey was done on the first day there may not be enough time to have all the schedule presenters and field the survey. On the second day there was ample time to finish the survey. A limitation of conducting the pre-survey on the second day is that, it might not reflect what social support was before coming to CARE. Peers may have connected on the first day and the perceived social support might have increased, so the change in perceived social support might show as lower between the pre-survey and post-survey.

There were sample limitations. Since there were only eight in-depth interviews and 25 pre-survey participants, the data might not have reflected what would be seen if all of CARE participants were interviewed and surveyed. With this small sample size, nothing definitive and statistically significant can be said about the CARE program. The sample was also a convenience sample of those willing and able to complete the in-depth interviews and pre-survey. I did not sample all the CARE participants, only people who were present and willing to be sampled. I also did not compare perceived social support of the CARE participants with ZSFG cancer survivors who do not attend CARE. Comparing perceived social support between those two groups can help demonstrate how perceived social support differs between CARE participants and non-CARE participants. Also since ZSFG cancer patients are unique and tend to be low-income and vulnerable, generalizing the findings to other cancer support groups is not advisable.

There are limitations in regards to the design of the survey. Written survey might also not be the best for those who lack literacy. Since the surveys were completed during the CARE session, people might not be fully truthful. Steps were taken to try to reduce pressure felt on displeasing staff by having interns and volunteers pass out and collect surveys. Survey were given during the session, so people are motivated to do it at that moment instead of taken home and forgotten. Asking for names on the survey may be a big limitation. People might not want to be fully truthful since they identified themselves and do not want to be too displeasing. Ways I tried to address this anxiety from writing their names on the

survey was saying the data will be pool together in a report, and will not affect their participation in CARE.

Another limitation of the project is that social support might not be what potential stakeholders from ZSFG want to know. Since CARE is housed in a hospital where health is of primary interest, perceived social support may not be what stakeholder want to know. Instead they might want something akin to health-related quality of life, but this construct is complicated to use for a program evaluation in ways discussed previously. One way we address this issue is by reporting ways social support has affected health-related factors such as sleep, emotional stability, and more as described by CARE participant testimony. In addition, there are many studies showing the linkage of social support with health-related benefits (Eisenberger, 2013).

CARE Recommendations

I recommend that CARE continue to investigate the social support aspect of CARE. It was shown to be a highly valued feature of CARE. A major reason people come to CARE is to speak with other cancer survivors. Both the in-depth interviews and the surveys showed that. Social support may also be promising because it can be a steppingstone to other desired health-related benefits such as improved sleep and emotional wellbeing. There may be other health-related benefits not captured in the interviews that use social support as a vehicle to improve health, so that should be explored. The mechanism seems to be that participants are getting social support from cancer survivors at CARE then getting experiential knowledge from others, gaining camaraderie, and building hope— leading to a more peaceful and productive life. This mechanism can be further explored and described to gain stakeholder support.

Having a short paper survey available during sessions seems the most sensible for obtaining data from CARE participants. Participants seemed to be okay with the paper surveys and even said it was best to complete the survey during CARE, so feedback is fresh in their minds. Giving immediate feedback may be important as ZSFG cancer survivors have many adversities and may not have the time

to complete the survey later. Short, clear and concise surveys are preferred since long surveys may be disliked by participants and may not get completed. Paper survey also were preferred since some CARE participants are older and may not be used to taking electronic surveys; however, in the future CARE participants may be open to online or electronic surveys.

CARE staff should use the surveys provided or design a survey similar to the one provided in the future. From the pilot pre-survey feedback, the post-survey can be improved by using a simpler worded Likert scale for the perceived social support survey. The wording is already modified in the surveys provided in appendix C and D. The previous wording in the pilot pre-survey made at least two CARE participants confused, so rephrasing was needed. Following the design of the post survey in appendix C and D for future surveying can help.

To satisfy certain stakeholders who needed health-related quantitative results, taking an inventory of health-related benefits since attending CARE may help. In the post-survey there is an inventory of health-related benefits; however, this inventory can expand. I suggest noting other health-related benefits and adding it to this inventory, so that information is captured. Showing the number and percentage of those gaining various health-related benefits may be what certain stakeholders want.

Suggestions for Research

Currently literature does not provide a standard method to evaluate peer cancer support groups, so I suggest further research to make this possible. Research would need to bring many different key stakeholders together such as program planners, funders, cancer care experts, cancer survivorship research experts, and most importantly cancer survivor social support participants. Ideally, what is evaluated should be a common construct of interest held by all the stakeholders listed.

A gold standard quantitative survey tool that measures efficacy of peer cancer support groups can make evaluation easier. More research should be done to work toward a gold standard survey tool. Having such a tool can make it easier to conduct a survey and compare programs. A standard survey

tool could make evaluation easier, but it will be difficult to develop since there are various program designs, populations of cancer survivors, and other complicating variables.

Another important suggestion for cancer support research is to understand the mechanisms of how peer support amongst cancer survivors leads to health benefits. A goal of some peer cancer support programs is to improve health. Therefore, understanding mechanism for adopting healthier practices through peer influence may be key in knowing what it takes to improving health and programing. To understand these mechanisms it is appropriate and necessary to employ qualitative research methods that gives more descriptive information.

Once extensive research is done on social support group evaluation, I urge an authority in cancer care to provide best practices on evaluation. This should include evaluation methods, quantitative survey tools, and justification on why these best practices work. If it is outlined, more peer cancer support groups can conduct rigorous and accurate evaluations. This type of evaluation can help peer cancer support group gain sponsor support, and improve programing.

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References

- Aaronson, N. et al. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: A Quality-of-Life Instrument for Use in International Clinical Trials in Oncology. *J Natl Cancer Inst* 85(5): 365-376. doi: 10.1093/jnci/85.5.365
- American Cancer Society. (n.d.). *Coping with Cancer*. Retrieved from <https://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects.html>
- American Society of Clinical Oncology. (n.d.) *Challenges to Implementing a Survivorship Program*. Retrieved from <https://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-4>
- Andrykowski, M. A., Lykins, E., & Floyd, A. (2008). Psychological Health in Cancer Survivors. *Seminars in Oncology Nursing*, 24(3), 193–201. <http://doi.org/10.1016/j.soncn.2008.05.007>
- Andrykowski, M. A., Cordova, M. J., Studts, J. L., & Miller, T. W. (1998). Posttraumatic stress disorder after treatment for breast cancer: Prevalence of diagnosis and use of the PTSD Checklist—Civilian version (PCL—C) as a screening instrument. *Journal of Consulting and Clinical Psychology*, 66(3), 586-590. doi:<http://dx.doi.org.ucsf.idm.oclc.org/10.1037/0022-006X.66.3.586>
- Aziz, N. (2002). Cancer Survivorship Research: Challenge and Opportunity *The Journal of Nutrition*.132(11), 3494S-3503S.
- Blinman, P., King, M., Norman, R., Viney, R., Stockler, M. (2012). Preferences for cancer treatments: an overview of methods and applications in oncology. *Annals of Oncology*.23(5), 1104-110.
- Bruera E, Kuehn N, Miller MJ, Selmsler P, & Macmillan K. (1991). The Edmonton Symptom Assessment System (esas): a simple method for the assessment of palliative care patients. *Journal of Palliative Care*. 1991(7), 6–9.
- Campbell, S., Phaneuf, M., & Deane, K. (2004) Cancer peer support programs—do they work?. *Patient Education and Counseling*. 55(1), 3—15, <http://dx.doi.org/10.1016/j.pec.2003.10.001>.

Centers for Disease Control and Prevention. (2014). *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*. Retrieved from:

Advancing Public Health Strategies. Retrieved from:

<https://www.cdc.gov/cancer/survivorship/pdf/plan.pdf>

Cancer Prevention Institute of California. (2016). The Greater Bay Area Cancer Registry. Annual

Incidence and Mortality Review, 2009-2013. Retrieved from

http://www.cpic.org/files/PDF/Cancer_Registry/Reports/2016_Annual_Report/2016_GBACR_Annual_Incidence_and_Mortality_Review_FINAL_061416.pdf

Cancer Research UK. (2014a). *What is cancer?* Retrieved from <http://www.cancerresearchuk.org/about-cancer/what-is-cancer>

Cancer Research UK, (2014b) *Stages of cancer*. Retrieved from <http://www.cancerresearchuk.org/about-cancer/what-is-cancer/stages-of-cancer>

Eisenberger, N. I. (2013). An Empirical Review of the Neural Underpinnings of Receiving and Giving Social Support: Implications for Health. *Psychosomatic Medicine*, 75(6), 545–556.

<http://doi.org.ucsf.idm.oclc.org/10.1097/PSY.0b013e31829de2e7>

Ferrell, B. et al. (2012). Quality of Life Patient/Cancer Survivor Version (QOL-CSV). *Measurement Instrument Database for the Social Science*. Retrieved from www.midss.ie

George Washington Cancer Institute. (2013). Best Practices in Patient Navigation and Cancer Survivorship Survey Results. Retrieved from

https://smhs.gwu.edu/gwci/sites/gwci/files/Best_Practices_Results_Summary-Final.pdf

Gottlieb, B. H., & Wachala, E. D. (2007). Cancer support groups: A critical review of empirical studies. *Psycho-oncology*, 16, 379–400.

Greer, J. A., Solis, J. M., Temel, J. S., Lennes, I. T., Prigerson, H. G., Maciejewski, P. K., & Pirl, W. F. (2011). Anxiety Disorders in Long-Term Survivors of Adult Cancers. *Psychosomatics*, 52(5), 417–423. <http://doi.org/10.1016/j.psych.2011.01.014>

- Hiatt, R., Ashworth, A. (2016). *The San Francisco Cancer Initiative*. Retrieved from http://www.sfcancer.org/sites/sfcancer.org/files/CancerinSanFrancisco_111616.pdf
- Hoey, L., Ieropoli, S., White, v., & Jefford, M., (2008). Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling*. 70(3), 315-337.<http://dx.doi.org.ignacio.usfca.edu/10.1016/j.pec.2007.11.016>.
- Jacobsen, PB., et al., (2005). Screening for psychologic distress in ambulatory cancer patients: a multicenter evaluation of the distress thermometer. *Cancer* 103(7):1494–1502
- Jemal, A., et al. (2017). Annual Report to the Nation on the Status of Cancer, 1975–2014, Featuring Survival. *Journal of the National Cancer Institute*, 109(9), djx030.
<http://doi.org/10.1093/jnci/djx030>
- Lee, R. (2013). *Using Mixed Methods for Community Based Research*. Retrieved from <https://www.une.edu/sites/default/files/7%20Using%20Mixed%20Methods%20for%20Community%20Based%20Research.pdf>
- Leigh, S. (1996). Defining our destiny. In B. Hoffman (Ed.), *A Cancer Survivor's Almanac: Charting the Journey* (pp. 261-271). Minneapolis, MN: Chronimed Publishing.
- Li, X., Chen, W., & Popiel, P. (2015). Perceived Social Support Measure [Database record]. Retrieved from PsycTESTS. doi: <http://dx.doi.org/10.1037/t44242-000>
- Malin J, Sayers E, & Jefford M. (Eds.). (2011). *What is quality health care for cancer survivors? Health Services for Cancer Survivors*. Pennsylvania: Feuerstein M and Ganz, 27-49.
- National Coalition for Cancer Survivorship. (2014). *Defining Cancer Survivorship*. Retrieved from <https://www.canceradvocacy.org/news/defining-cancer-survivorship/>
- National Comprehensive Cancer Network. (n.d.-a) *Cancer Staging Guide*. Retrieved from <https://www.nccn.org/patients/resources/diagnosis/staging.aspx>
- National Cancer Institute. (n.d.-b) *Side Effects*. Retrieved from <https://www.cancer.gov/about-cancer/treatment/side-effects>

National Cancer Institute. (n.d.-c). *Coping with Cancer: Feelings and Cancer*. Retrieved from

<https://www.cancer.gov/about-cancer/coping/feelings/depression-hp-pdq>

National Cancer Institute. (n.d.-d) *Grid Enabled Measure Database*. Retrieved from [https://www.gem-](https://www.gem-beta.org/public/MeasureList.aspx?cat=2&viewall=true&kwd=cancer+survivorship&scont=10&sconstruct=0)

[beta.org/public/MeasureList.aspx?cat=2&viewall=true&kwd=cancer+survivorship&scont=10&sconstruct=0](https://www.gem-beta.org/public/MeasureList.aspx?cat=2&viewall=true&kwd=cancer+survivorship&scont=10&sconstruct=0)

National Cancer Institute. (2015). *What is Cancer?* Retrieved from [https://www.cancer.gov/about-](https://www.cancer.gov/about-cancer/understanding/what-is-cancer)

[cancer/understanding/what-is-cancer](https://www.cancer.gov/about-cancer/understanding/what-is-cancer)

Parry, C., Kent, E. E., Mariotto, A. B., Alfano, C. M., & Rowland, J. H. (2011). Cancer Survivors: A Booming Population. *Cancer Epidemiology, Biomarkers & Prevention : A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology*, 20(10), 1996–2005. <http://doi.org/10.1158/1055-9965.EPI-11-0729>

Pirl, W. (2004). Evidence Report on the Occurrence, Assessment, and Treatment of Depression in Cancer Patients. *Journal of the National Cancer Institute. Monographs*. 2004(32): 32-39. doi: 10.1093/jncimonographs/lgh02

President's Cancer Panel. (2004). *Living Beyond Cancer: Finding a New Balance*. Retrieved from

<https://deainfo.nci.nih.gov/advisory/pcp/archive/pcp03-04rpt/Survivorship.pdf>

Reuben, S. (2004). *Living Beyond Cancer: Finding a New Balance*. *United States Department of Health and Human Services*. Retrieved from:

<https://deainfo.nci.nih.gov/advisory/pcp/annualReports/pcp03-04rpt/Survivorship.pdf>

San Francisco Health Improvement Partnership. (2016a). *All Cancer Incidence Rate*. Retrieved from

<http://www.sfhip.org/index.php?module=indicators&controller=index&action=view&indicatorId=162&localeId=275>

San Francisco Health Improvement Partnership. (2016b). *Age-Adjusted Death Rate Due to Cancer*.

Retrieved from

<http://www.sfhip.org/index.php?module=indicators&controller=index&action=view&indicatorId=95&localeId=275>

- Shen, C.-C., Hu, Y.-W., Hu, L.-Y., Hung, M.-H., Su, T.-P., Huang, M.-W., ... Liu, C.-J. (2013). The Risk of Cancer in Patients with Generalized Anxiety Disorder: A Nationwide Population-Based Study. *PLoS ONE*, 8(2), e57399. <http://doi.org/10.1371/journal.pone.0057399>
- Siegel, R. et al. (2012). Cancer treatment and survivorship statistics, 2012. *Cancer Journal for Clinicians*, 62(4), 220–241.
- Steinberg, T., et al. (2009) Prevalence of emotional distress in newly diagnosed lung cancer patients. *Support Care Cancer*. 17(1493). doi:10.1007/s00520-009-0614-6
- Ware JE, Jr, Kosinski M, Keller SD. "A 12-Item Short-Form Health Survey: Construction of Scales and Preliminary Tests of Reliability and Validity." *Medical Care*. 1996;34(3):220–33
- Winstead-Fry, P., & Schultz, A. (1997). Psychometric assessment of the Functional Assessment of Cancer Therapy-General (FACT-G) scale in a rural sample. *Cancer*, 79(12), 2446-2452.

Appendix A

SWOT Analysis Table

SWOT Analysis Table	
Table analysis strengths, weaknesses, opportunities, and threats	
<u>Strengths</u>	<u>Weaknesses</u>
<ul style="list-style-type: none"> CARE has loyal participants who have been coming for years 	<ul style="list-style-type: none"> CARE was created when there was little cancer survivorship research on best practices
<ul style="list-style-type: none"> CARE is one program within the Community Wellness Program that has many health and wellness promoting programs 	<ul style="list-style-type: none"> CARE’s mission and goals are very broad
<ul style="list-style-type: none"> CARE is in ZSFG which is where participants get medical care 	<ul style="list-style-type: none"> CARE staff has not done an extensive formal evaluation capturing what participants consider most valuable about CARE
<ul style="list-style-type: none"> CARE has established a network of loyal guest speakers 	<ul style="list-style-type: none"> CARE has not created evaluation protocols based on a standard
<ul style="list-style-type: none"> CARE gets referrals from clinics and partners with clinical departments 	<ul style="list-style-type: none"> CARE is not getting many referrals from other clinics such as Urology, Geriatric Clinic, Neurology, Pain consultation, Plastic Surgery, Pulmonary, and Dermatology
<ul style="list-style-type: none"> CARE already has relationships with foundations that could fund 	<ul style="list-style-type: none"> CARE’s pool of endowment money have been diminishing
<u>Opportunities</u>	<u>Threats</u>
<ul style="list-style-type: none"> CARE staff can ask participants and guest speakers for feedback 	<ul style="list-style-type: none"> There is no national standard method and survey tool to evaluation cancer peer support groups
<ul style="list-style-type: none"> CARE staff could get advice and feed back from non-CARE Community Wellness staff that run community based programs 	<ul style="list-style-type: none"> If CARE does not get funding it need to operate, CARE could die
<ul style="list-style-type: none"> ZSFG clinical staff and CARE staff can work together to serve CARE participants 	<ul style="list-style-type: none"> CARE participants have limited resources and knowledge to help CARE initiatives continue by themselves
<ul style="list-style-type: none"> CARE would work with community organizations outside of ZSFG to gain support 	<ul style="list-style-type: none"> Clinics referring to CARE are not getting updates from CARE and they may not see how CARE participants’ health or wellbeing are improving
<ul style="list-style-type: none"> The foundations that have a relationship with CARE can give CARE feedback on the program and advise on how to gain more support, especially financial support 	<ul style="list-style-type: none"> It may be hard to substantiate sustaining CARE if other cancer support programs offer the exact same value.

Suggestions for CARE:

III. OPINION ON THE VISION OF CARE

a. Developing the Vision of CARE with the participants

i. We are working on a motto that summarizes what CARE stands for. In one phrase describe what CARE should stand for?

Probe: 1. What should CARE's motto be?

IV. GETTING FEEDBACK

b. Asking for feedback in the future

i. If you had a suggestion or a comment about a CARE session, how would you communicate it?

- Probe:
1. Would you feel comfortable giving feedback in person to staff? If so, who?
 2. Would you feel comfortable giving feedback on the phone?
 3. Would you feel comfortable giving feedback in a survey, online or paper, after the CARE session?
 4. Would you feel comfortable giving feedback through an anonymous comment box?

c. Feedback on CARE

i. Is there anything else you want to share with me about CARE?

Other competing support programs:

V. OTHER RESOURCES

a. Other resources used by CARE participants

i. What other support programs are you involved in?

Probe: 1. What do you get from that support program that you don't get from CARE?

ii. If CARE didn't exist where else or how else would you get the support you get from CARE?

Closing statement: Thank you so much for participating in this interview. The information you provided is valuable and will help CARE evolve, so CARE can provide the best support to its participants.

In the future, if you have questions, comments, or need support, please contact me at Glenda.Kith@sfdph.org or come to the Community Wellness Center.

Appendix C
CARE Pilot Pre-survey (English)

This survey is confidential. It will be combined into a report, and provided to CARE for program improvement. Your responses will NOT affect your participation in CARE.

1. **Name: First, Last initial** _____, _____.

2. **What is your age?** _____

3. **Gender:** Male Female Other

4. **Race/Ethnicity:** (Check ALL that apply)

African American/African

Caucasian

Asian/Pacific Islander

Latino/Chicano

5. **Are you:** (Check ONE)

(1) New to CARE

(2) Somewhat familiar with CARE

(3) CARE Veteran

5a. **How long have you attended CARE (months/years)?** _____/_____

6. **Describe your circumstances when you first joined CARE:** (Check ONE)

I have been diagnosed with cancer

I have not been diagnosed with cancer, but I am a family member/friend of someone diagnosed with cancer. If you selected this option SKIP question 7.

Continue to the next page.

7. Where are you in the cancer process? (Check ALL that apply)

Diagnosed with cancer in the last 6 months <input type="checkbox"/>	Currently in cancer treatment Within last 6 months <input type="checkbox"/>	Done with treatment in the previous year <input type="checkbox"/>	Done with treatment over a year ago <input type="checkbox"/>
--	--	--	---

8. Who told you about CARE? (Check ALL that apply)

- Friend
- Medical Provider
- Cancer Navigator
- Social Worker
- Community Wellness Center Staff
- Other: _____

9. Do you feel you heard about CARE...

- Too early
- At the right time
- Too late

Why?: _____

10. In the past 12 months I was in extreme financial need and didn't have money to pay rent, housing bills, food and/or medicine...

- Often True
- Sometimes True
- Never True

Continue to the next page.

11. What is the main reason you first came to CARE? (Check ALL that apply)

- To talk with other cancer survivors who understand
- To get emotional support
- To learn more about cancer from presenters
- To get connected to resources such as meal assistance, housing, etc.
- To get a healthy dinner
- Other: _____

Below is question regarding social support (Check one box in each line)

12. Please read each statement and indicate how much you agree or disagree.	Definitely Yes	Yes	Neither yes or no	No	Definitely No
12a. I know someone I can confide in about my problems relating to cancer.					
12b. I have someone who can give me advice on crises relating to my cancer.					
12c. I have someone who gives me information to help me better understand my cancer.					
12d. I have someone to help with daily chores if I was sick.					
12e. I have someone I can have a good time with.					

12. Tell us how you hope CARE could help you improve your life.

13. What cancer do you have? (OPTIONAL, Answer only if comfortable)

Stage: Stage 1 Stage 2 Stage 3 Stage 4

Last Page.

*Thank you for participating!
This information will help us improve CARE.*

Appendix D
CARE Post-survey (English)

This survey is confidential. It will be combined into a report, and provided to CARE for program improvement. Your responses will NOT affect your participation in CARE.

1. **Name: First, Last initial** _____, _____.

2. **What is your age?** _____

3. **Gender:** Male Female Other

4. **Race/Ethnicity:** (Check ALL that apply)

African American/African

Asian/Pacific Islander

Caucasian

Latino/Chicano

5. **Are you:** (Check ONE)

(1) New to CARE

(2) Somewhat familiar with CARE

(3) CARE Veteran

5a. **How long have you attended CARE (months/years)?** _____/_____

6. **What is the main reason you first came to CARE?** (Check ALL that apply)

To talk with other cancer survivors who understand

To get emotional support

To learn more about cancer from presenters

To get connected to resources such as meal assistance, housing, etc.

To get a healthy dinner

Other: _____

7. Attending CARE has prepared me to...	Agree	Disagree	Neither agree or disagree
7a. Better accept my cancer diagnosis			
7b. Select a cancer treatment plan			
7c. Better manage my side effects (such as pain, focus, etc.)			
7d. Emotionally deal with my cancer			
7e. Eat healthier			
7f. Sleep better			
7g. Exercise more regularly			
7h. Communicate better with my health provider			
7i. To connect with other cancer support programs (such as Project Open Hand, Second Opinion, etc.)			
7j. Communicate better with my loved ones about my cancer			
7k. Become more productive at work or home			
7l. Be more aware of my physical, mental and emotional issues			
7m. Other: Specify: _____			

Continue to the next page

Below is question regarding social support (Check one box in each line)

8. Please read each statement and indicate how much you agree or disagree.	Definitely Yes	Yes	Neither yes or no	No	Definitely No
8a. I know someone I can confide in about my problems relating to cancer.					
8b. I have someone who can give me advice on crises relating to my cancer.					
8c. I have someone who gives me information to help me better understand my cancer.					
8d. I have someone to help with daily chores if I was sick.					
8f. I have someone I can have a good time with.					

9. What would you like CARE to change? (Check all that apply)

- More time to check-in in a group if people have updates and news to tell
- Having more time to socialize at the end
- Having CARE staff drop-in office hours
- Healthier food choices
- Other (if no changes desired write "None"): _____

10. What cancer do you have? (OPTIONAL, Answer only if comfortable)

Stage: **Stage 1** **Stage 2** **Stage 3** **Stage 4**

11. Do you have comments or feedback on CARE?

Last Page.

Thank you for participating! This will help us improve CARE.

Appendix E

Table 7		
Pre-survey Cancer Information		
Cancer type	Breast	6
	Chronic Lymphocyte Leukemia	2
	Colon	1
	Gallbladder	1
	Lung	2
	Lymph	1
	Myeloma	1
	Stomach	1
	Thyroid	1
	Tongue	1
	Prefer not to say	8
	Stage	Stage 1
Stage 2		5
Stage 3		2
Stage 4		7
No stage indicated		10
Place in Cancer Continuum	Diagnosed with cancer 6 months ago	3
	Currently in treatment within the last 6 months	8
	Done with treatment in the previous year	3
	Done with treatment over a year ago	9
	Nothing indicated	3

Appendix F

Table 8		
Familiarity with CARE		
Familiarity with CARE		
Percent		
(Number)	New to CARE	21%(5)
	Somewhat Familiar with CARE	29%(7)
	CARE Veteran	50%(12)
Length of CARE membership		
Average number of years (Range)	3.5 years (0-11 years)	