

Effect of Social Support on Health Empowerment and Perceived Well-Being in Adults Impacted

By Cancer: A Program Evaluation.

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### Abstract

**Background:** Cancer impacts the lives of millions of patients, families and caregivers annually leading to chronic stress, a sense of powerlessness, and decreased autonomy. Social support may improve health empowerment and lead to increased perception of well-being.

**Purpose:** The purpose of this project was to evaluate the effectiveness of social support provided by a cancer support agency on health empowerment and perceived well-being in adults impacted by cancer.

**Conceptual Framework:** The Health Empowerment Theory maintains that perceived well-being is the desired outcome; mediated by health empowerment through social support, personal growth, and purposeful participation in active goal attainment.

**Methods:** Twelve adults impacted by cancer agreed to complete online questionnaires at baseline and at 12 weeks after beginning participation in social support programs provided by a cancer support agency. Instruments included: Patient Empowerment Scale, The Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS), and The Office of National Statistics (ONS) Subjective Well-Being Questions.

**Results:** Four participants completed pre and post surveys. An increase was seen in empowerment scores (pre  $M = 1.78$ ,  $SD = 0.35$  and post  $M = 3.05$ ,  $SD = 0.42$ ). There was no increase in perceived well-being: SWEMWBS pre ( $M = 3.71$ ,  $SD = 0.76$ ), post ( $M = 3.57$ ,  $SD = 0.65$ ); ONS pre ( $M = 7.69$ ,  $SD = 1.36$ ), post ( $M = 6.59$ ,  $SD = 1.52$ ).

**Implications:** The data showed an increase in health empowerment scores after utilizing social support programs, lending support to the agency's support strategies. It is recommended that the measures be included in surveys routinely conducted by the agency to continue to assess the impact of programming on health empowerment, and perceived well-being.

Keywords: empowerment, well-being, cancer, social support, intervention

Effect of Social Support on Health Empowerment and Perceived Well-Being in Adults Impacted

By Cancer: A Program Evaluation

The diagnosis of cancer immediately elicits a myriad of negative emotions and fear. Both patients and loved ones, have difficulty processing and coping with this life-changing event. Community social support agencies provide assistance to individuals who have been impacted by cancer. These agencies provide tools and opportunities to process the emotions of a cancer diagnosis through positive social support interventions, which may improve health empowerment and ultimately increase the perception of well-being.

### **Background and Significance**

In the United States the lifetime average of developing cancer is 40%. Cancer is the second leading cause of death with approximately 1.6 million newly diagnosed, and half a million deaths estimated for 2015 (Siegel, Miller, & Jemal, 2015). Historically, the diagnosis of cancer was viewed as a terminal illness invoking fear and uncertainty. This perception is rapidly changing as researchers are developing new treatments making it possible for patients to live longer than ever before; a cancer diagnosis is now often treated as a chronic illness (Siegel et al., 2015).

According to the National Cancer Institute: Surveillance, Epidemiology, and End Results Program [NCI; SEER] (2015), between 1991 and 2011 the overall cancer death rate due to cancer decreased by 22% and the average five-year survival rate increased by 20% for all types of cancer. However, patients are often left with chronic physical and psychological ramifications of their disease (Regan et al., 2014).

Cancer treatments such as chemotherapy, radiation, and surgery have side effects including pain, fatigue, nausea, gastrointestinal upset, and hair loss. Depending on the type of

cancer, there may be higher rates of depression and anxiety, disfigurement, or sexual dysfunction, which can lead to altered body image, decreased partner intimacy and increased depression (Sengul et al., 2014; Yilmaz et al., 2015; Hughes et al., 2015, Paterson et al., 2013).

The diagnosis of cancer impacts patients and the families physically, emotionally, economically, and socially (Sengul et al., 2014). Much of their time is spent at doctor visits, outpatient treatment centers, and hospitals. Social networks that were previously embedded into one's life continue but are often disrupted. However, research demonstrates that positive social support and perceived social support can directly impact both mental and physical health (Mosher, 2013) (McCorkle, 2011).

The health risks of increased stress on the biological systems can be severe. Hughes et al. (2014) studied women with breast cancer and suggested a connection between lowered social support at the beginning of cancer treatment and higher levels of pain and depressive symptoms as well as IL-6 (a pro-inflammatory cytokine) inflammation at the six month post treatment compared to those who reported higher levels of social support at the beginning of their treatment. In a recent meta-analysis (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015) examining mortality outcomes and social support, researchers found that social isolation, loneliness, and living alone is associated with a 25-30% increase in mortality. Other studies reveal the negative impact that stress has on the overall survival rates of cancer patients (Reuter, Gupta, Chattervedi & Aggarwal, 2010).

Cancer affects not just the individual, but the family as well. Loved ones provide support to the patient as well as dealing with their own emotions about an uncertain prognosis. And as time goes on, the patient's physical needs may increase, leaving the family to cope with increasing challenges. This may not be an overwhelming burden for everyone, but often,

caregivers are aging spouses or other family members who are not able to continue the demanding physical care required by declining patients. Caring for an individual with cancer is physically and psychologically challenging and takes a toll on a caregiver's health as well (Hayman et al., 2001). Romito, Goldzweig, Cormio, Hagedoorn, and Anderson (2013) suggest the need for better caregiver support and discharge education plans similar to that of stroke and cardiac patients, in hopes to minimize personal financial loss and decrease the additional burden on the healthcare system as well as the public welfare system.

### **Social Support**

While the definition of support varies widely, it generally falls into one of three categories: emotional support, physical cares and support, or educational/informational support during a difficult time (Holt-Lunstad & Uchino, 2015). The effect of social support on one's health is clearly documented. In a landmark social sciences study, House, Umberson, and Landis (1988) proposed that social support, relational demands, and social regulation are the processes that are produced by the social structures of community togetherness and unions; whereby these processes have a direct positive or negative effect on an individual's health. A recent study by Puetz, Morley, and Herring (2013) describes the benefits of creative art therapies by cancer patients both in the hospital and ambulatory settings. The study reports a significant reduction in pain, anxiety, and depression with a related increase in quality of life and overall-well-being.

### **Health Empowerment**

Health empowerment is one aspect of the larger picture of overall well-being. It is the individual's belief that they have the innate power and resources to accomplish goals and overcome life events (Diener & Biswas-Diener, 2005) as well as confidence and self-esteem (Shearer & Reed, 2004). The definition of empowerment is subjective depending on the context

in which it is used. Brunet et al (2015) defines empowerment as a one's ability to govern or regulate the experiences and challenges while maintaining a sense of control over his or her life; the individual will understand and participate, utilize available resources and take actions that will reduce anxiety, improve self-management which will improve quality of life and overall well-being. An individual with cancer may feel a sense of powerlessness, as they are frequently navigating countless appointments that fill up their calendars, and are constantly given information that is often beyond their comprehension.

### **Perceived Well-Being**

Perceived well-being is generally recognized as overall harmony and life satisfaction (Gueldner et al., 2005), or positive interpretations of one's life, including pleasant feelings, accomplishments, and life satisfaction (Diener & Biswas-Diener, 2005). It is one's thoughts and feelings about their own happiness, and how their life is going (Graham, 2010).

### **Internal Evidence**

A non-profit cancer support agency in a metropolitan area of the southwestern United States (U.S.) providing social support programs to members of the community experiencing a cancer diagnosis requested assistance evaluating current social support programming on client outcomes. Clients currently have cancer, are cancer survivors, or are a loved one or caregiver of someone with cancer. The agency offers social support in many ways, and is interested in determining if programs provide a sense of empowerment and overall well-being in participants. Such information can be utilized to enhance program effectiveness. The agency's ability to obtain funding is also impacted by the ability to demonstrate program effectiveness.

### **Problem Statement**

Cancer is a global concern. It does not discriminate between age, gender, race or ethnicity. It has an effect on every part of one's life – physical, emotional, spiritual, and social; which impact a person's sense of well-being. Participation in formal and informal social support activities may increase a sense of health empowerment improving perceived well-being and health status.

### **PICOT**

This inquiry has led to the clinically relevant question: In adults with cancer and/or their caregivers (P), how does the use of social support activities and services (I), compared to not using social support (C), affect empowerment and overall well-being (O) over 12 weeks (T)?

### **Search Strategy**

Literature searches included EBSCO host, ProQuest PsychInfo, and NCBI Pubmed. Keywords/Boolean phrases used were: cancer and/OR empowerment OR well-being, social support intervention, and *not* diabetes. Limiters included year (no earlier than 2005), full text, English language, and peer reviewed. A total of forty-two abstracts were reviewed, and a total of six articles were selected.

### **Evidence Synthesis**

A total of six studies were chosen for review. The rapid critical appraisal approach was utilized to evaluate the evidence. The studies chosen are of varying levels of evidence from Level II to Level VI, and also vary greatly in the designs and methods used. Of the six studies reviewed two were longitudinal – one of which is a 5-year random controlled trial, two mixed-methods, and two systematic reviews. Of the studies reviewed, the majority are qualitative with Levels V or VI and one Level II. All were studies that focused on the influence of social support interventions or perceived support on health empowerment and perceived well-being outcomes.

Direct correlations included an improvement in well-being after social support and group participation, as well as community based programs enable and empower participants (Hoey, 2008); Hughes, (2014), McCorkle, (2011), Paterson, (2013), Puetz, (2013), Stang, (2009), Ussher, (2005). Most studies were centered on the cancer patient, with others addressing the caregivers (Haymen, 2001; Mosher, 2013; Regan, 2013; Romito, 2013). Overall, all studies reviewed displayed a broad degree of sample demographics including gender, age (>18 years), socioeconomic status, and types of cancer.

There are several factors to be considered when evaluating research in this population. First, there can be a high rate of attrition due to the nature of the disease. Although cancer is a global concern, cultural factors may influence results. The majority of the studies were funded by federal or national grants, or no funding was declared. Potential areas for bias were researcher affiliation with a major health institution, samples of convenience, and low level and limited evidence.

However, the overarching theme of these articles was that social support interventions do provide a sense of empowerment, togetherness, and hope, increasing overall well-being during times of stress.

### **Purpose Statement**

The purpose of this project was to evaluate the effectiveness of social support provided by a cancer support agency on health empowerment and perceived well-being in adults impacted by cancer.

### **Evidence Based Practice Model**

Rosswurm and Larrabee's Model for Evidence-Based Practice Change (1999) was used to guide this project. There are six steps to the model, but this project focused on the first three

steps – 1.) Assess the need for change, 2.) Link the problem with interventions and outcomes, 3.) Synthesize the best evidence (Rosswurm & Larrabee, 1999). The need for change is based on the support community's request for program evaluation. The problem is defined as an increasing number of individuals experiencing a cancer diagnosis who may have physical, emotional, and/or psychosocial unmet needs that may benefit from social interventions offered through the organization which evidence shows can increase a sense of empowerment and overall well-being. The fourth step in the Rosswurm and Larabee Model (1999) is to design a change in practice. After internal evidence is collected and analyzed, the information can be used to inform future programming.

### **Theoretical Model**

The Health Empowerment Theory (Shearer, 2009) provided the conceptual framework for this project. According to Shearer (2009) health empowerment stems from a fusion of resources, both personal and social-contextual that may include self-capacity, support from social services and networks available to the individual. It is a deliberate course of action an individual takes in order to change oneself and their environment, to recognize patterns, and draw strength from inner resources for their well-being and goal attainment (Shearer, 2009). Health empowerment is defined as “a dynamic health process that emphasizes ‘purposefully participating in a process of changing oneself and one’s environment, recognizing patterns, and engaging inner resources for well-being’”. Health empowerment is realized through personal growth, self-acceptance, purpose and social support; these constructs guide the individuals’ awareness, choices, and intentional actions, which lead to perceived well-being (Shearer, 2009). The desired health outcome is ultimately perceived well-being. Health Empowerment Interventions consist of personal resources such as self-capacity building to acknowledge and

reinforce personal strengths and self-advocacy, and social contextual resources to reinforce and promote social connections, resources, and promote problem-solving skills. Health empowerment is conceptualized as a mediator through, which through personal growth, self-acceptance, social support, utilization of social services, and defining one's purpose in life is achieved.

## **Methods**

### *Ethics*

IRB approval was applied for and exemption was granted on September 15, 2016. CITI training for human participants were completed. Agency approval and a site letter were obtained.

### *Setting*

The project was conducted at a non-profit community cancer support agency located in the southwest United States. The organization reports serving 1,875 clients in 2014. Clients consist of individuals of all ages, cancer diagnosis/status, including friends, loved-ones and caregivers who have also been impacted by a cancer diagnosis.

### *Participants*

Inclusion criteria were: adults over the age of 18 with a current or previous diagnosis of cancer, or a friend, relative, loved one or caregiver of someone with a cancer diagnosis. Individuals under the age of 18, unable to consent, and those could not read or write English were excluded.

### *Procedures*

The student project director presented information about the project at the meetings using the recruitment script and answered any questions at weekly newcomer meetings. No

advertisements or flyers were used to recruit participants. The time period for data collection was September 2016 to March 15, 2017. No compensation was provided to participants.

Once individuals agreed to participate, they received an email that included the consent letter with a link to the surveys through the student project directors privately held Survey Monkey platform. Participation in the survey was considered consent. The link was available to the participant for seven days following notification for both the initial survey and the 12-week follow-up survey. At twelve-weeks, the participant received a second email with the survey link for the follow up survey, which also remained open for seven days. Participants generated a unique, anonymous identifier for both the pre and post intervention surveys, online and paper versions. Paper surveys were available, however no participants requested the paper version.

### *Interventions*

The community support agency uses five pillars or umbrellas to encompass their support programs; they include support services, education, healthy lifestyle, social connections and resource and referral. Clients may join any class or program at no cost to them. This project did not introduce any new interventions or attempt to manipulate the type or frequency of services attended by participants.

### *Outcome Measures*

Outcomes were measured by the use of three tools. Health Empowerment was measured using The Patient Empowerment Scale (PES) (Bulsara, Styles, Ward & Bulsara, 2006). The PES consist of 15 questions such as 'I am capable of handling my/my loved ones illness' measured on a four-point Likert-scale ranging from 'strongly agree to strongly disagree' whereas a higher score equates to a higher level of empowerment. Psychometric testing was conducted by the instrument developers demonstrating that the instrument can be used in assessing level of

empowerment amongst cancer patients (Bulsara, Styles, Ward, & Bulsara 2006). No other studies were found to report additional validity or reliability although, communication with the primary developer indicated there is a large prostate cancer study currently in progress in the United Kingdom using the tool to evaluate health empowerment levels for men.

Participant well-being was measured by multiple short form questionnaires developed by the Centre for Well-being and The New Economics Foundation for the Office of National Statistics (ONS), and the Short Warwick- Edinburgh Mental Well-being Scale (SWEMWBS, 2015). The SWEMWBS is seven questions on a five-point Likert-scale which reflect the individual's thoughts and feelings using questions such as "I've been feeling optimistic about the future" Stewart-Brown et al., (2011) reports a Cronbach's  $\alpha$  (0.89). Validity has been assessed by correlating well-being with mindfulness, emotional intelligence and positive affect revealing weak to strong positive correlations ( $r = .13$  to  $.61$ ) (Haver, Akerjordet, Caputi, Furunes, & Magee, 2015).

The ONS questionnaire consists of four questions on a 0-10 point scale, and reflects the clients' feelings about life satisfaction, happiness, and anxiety. Diener (2011) reports a Cronbach  $\alpha$  (0.8 and 0.96) on a meta-review of the reliability of the subjective well-being measures of life satisfaction.

#### *Data Collection*

Twelve clients agreed to participate, six completed the pre-intervention survey, and four completed the post-intervention survey at 12-weeks. The data was stored in the private, password protected account until data extraction into SPSS 24 occurred for analysis.

#### *Results*

Demographic data shows all participants were white, female, 50% were married/partnered with the other 50% separated or divorced. All participants were over the age of 31 years; Most of the clients were patients (83%). Three (50%) were newly diagnosed, 66% were currently undergoing treatment, and 16% were in remission (Table 1). Four participants completed pre and post surveys. An increase was seen in empowerment scores (pre  $M = 1.78$ ,  $SD = 0.35$  and post  $M = 3.05$ ,  $SD = 0.42$ ). However, there was no increase in perceived well-being as measured by the SWEMWBS (pre-intervention scores  $M = 3.71$ ,  $SD = 0.76$  and post-intervention scores  $M = 3.57$ ,  $SD = 0.65$ ); or the ONS (pre-intervention scores  $M = 7.69$ ,  $SD = 1.36$  and post-intervention scores  $M = 6.59$ ,  $SD = 1.52$ ).

## Discussion

In spite of the small sample size, results supported increased health empowerment after 12 weeks of participation in social support activities. Shearer (2009) describes health empowerment as a precursor to perceived well-being therefore, overtime, there may be an increase in perceived well-being.

The results of this project align with other research in this field. Ussher & colleagues (2006) relate utilization of cancer social support groups to an increase in confidence and a sense of control as it relates to self, cancer, and interactions with others – specifically health care providers – which increases health empowerment. Stang & Mittelmark (2009) report social support interventions that focus on intrapersonal, interactional, and behavioral components increase health empowerment. Additionally, models of peer social support methods were reviewed by Hoey et al. (2008), which showed that regardless of the method, contact with others with a shared cancer experience provides psychosocial and emotional benefits leading to an increased sense of health empowerment.

**Limitations**

There were a number of barriers and limitations during this project. There were two new-member meetings in which there were no participants. The project also was conducted over the Christmas and New Year holidays, which may have contributed to the low participation. Additionally, this is a vulnerable population in which fatigue is common and placing an additional burden of completing surveys may lower participation.

**Conclusion and Implications**

Results of this project lend support to programming conducted by a cancer support agency in southwestern United States to provide social support to participants impacted by cancer to promote health empowerment. Although the exact mechanism is not fully understood, research demonstrates that social support improves health empowerment and perceived well-being measures for patients and caregivers experiencing the diagnosis of cancer. Further study is needed to investigate the specific social support strategies most effective in improving health empowerment and links to perceived well being.

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Table 1

*Demographic Data*Pre-intervention *n*=6

Gender	Female	83%
	Male	16%
Age	By Intervals	2 (31-50), 2 (51-69), 2 (70+)
Ethnicity	Caucasian	100%
Marital Status	Married/Partnered	50%
	Divorced/Single	50%
Patient or Caregiver	Patient	83%
	Caregiver	17%
Treatment Status	New Patient	3 – 50%
	Undergoing Treatment	4 – 66%
	Remission	1 – 16%