The Relation between Behavioral and Emotional Changes in Cancer Patients during

Their Treatment and Their Perceptions of Family Involvement

by
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ABSTRACT

Particular aspects of family support were examined in 19 female and 3 male cancer survivors using a comprehensive survey composed of 5 previously created surveys, and 14 additional questions that were meant to obtain a perspective of how the participant and their family interacted during treatment. Results show significant correlations between strong family support and areas such as decreased mental health problems, increased physical activity, and better dietary choices. However, contrary to the hypothesis, there were no significant correlations observed between communication, adjustment to cancer, and problem-solving. In summary, the results from the present study suggest that strong family support and involvement can be helpful in areas such as decreasing mental health problems, increasing physical activity, and better dietary choices. Future research with more participants and their families is needed to better understand the relation between types of family support and adjustment to a cancer diagnosis.

TABLE OF CONTENTS

LIST OF APPENDICES

CHAPTER I

Introduction/Literature Review

In 2017, there were approximately 1,688,780 people in the United States living with some form of cancer, not including the territory of Puerto Rico (ACS, 2017). One of these people was my father, Scott Lusins, who had been undergoing cancer treatments and complication reversal surgeries since I was 12 years old. My father changed a lot since his treatment began back in 2010, especially when it came to his physical appearance and how he behaved. With hindrances such as a colostomy bag, an overwhelmingly large hernia, and sciatica that prevented him from doing most menial physical tasks, his physical, emotional, and cognitive health deteriorated over time. Over the course of these past nine years, my father has experienced more changes than most people experience in their lives in terms of health. Unfortunately, my family and I have never known how to help him because we lacked the ability to communicate with him effectively about his condition. For this reason, I have been particularly interested in studying the relation between perceived family support by cancer survivors and their experiences during treatment.

For cancer patients and survivors, one of the most important things that contributes to their behavior over the course of their treatment is social support and/or family involvement. Although there have been studies that show how a patient and the patient's loved ones' behaviors changed after receiving a cancer diagnosis and how their support structures endured these changes over time (Edwards & Clarke 2004; Hilton 1996; Lewis, Hammond & Woods 1993), little research has been conducted on cancer

survivors' perceptions of family involvement on their outlook and behaviors during their treatment, and the support mechanisms they find particularly helpful.

Quality of Life/Mental Health

One important thing to keep in mind while observing a cancer survivor's journey through his or her treatment is what the survivor's quality of life was like during treatment and what specific factors contributed to the person's quality of life. It is also important to consider how mental health is associated with an individual's ability to deal with a cancer diagnosis and/or treatment. A study by Parker, Baile, Moor, and Cohen (2003) set out to identify psychosocial predictors of quality of life. Outpatients from the University of Texas M.D. Anderson Cancer Center participated in this study; patients were at least 18 years old and had been diagnosed at least one month before. A total of 351 people completed the questionnaire, which included the *Interpersonal Support Evaluation List* (Cohen & Willis, 1985), the *State-Trait Anxiety Inventory* (Spielberger, Gorsuch, & Lushene, 1970), the *Center for Epidemiologic Studies-Scale* (Radloff, 1977), and the *Medical Outcomes Study (MOS) 12-item Short-Form Health Survey* (Ware, Kosinski, & Keller, 1996). This study separated demographic and cancer characteristics into the physical health domain (e.g., general health, activity levels) or the mental health domain (e.g., emotional problems/stressors) depending on how they affected the patient's quality of life.

Parker et al. (2003) concluded that factors such as time since diagnosis and type of cancer had no effect on participants' adjustment and quality of life, but gender played a significant role on reported quality of life in both the physical and mental health domain. Women reported higher levels of anxiety and depression and lower quality of

life in both the physical health and mental health domain. Recurrence of cancer—as 31%
of the participants experienced recurrence—and whether or not the patient was currently
undergoing treatment only affected the physical domain of quality of life, whereas the
mental health domain was affected by factors including stage of disease and social
support (Parker et al. 2003).

Although undergoing treatment presents the possibility of a lower quality of life,
it is also possible that patients and their families encountered some type of mental stress,
too. A study by Compas et al. (1994) observed the relation between the number of and
seriousness of cancer characteristics and symptoms of anxiety/depression in cancer
patients, and their spouses and children. The surveys used in this study include the
Children's Depression Inventory (Kovacs, 1980), the *Revised-Children's Manifest
Anxiety Scale* (Reynolds & Richmond, 1997), the *Youth Self Report* (Achenbach, 1991),
the *Impact of Event Scale* (Horowitz, Wilner, & Alvarez, 1979), and the *Brief Symptom
Inventory* (DeRogatis, 1993).

Stage of cancer, SEER 5-year survival ratings, time since diagnosis, and
perceptions of seriousness and stressfulness of the cancer were all characteristics that
correlated with symptoms of anxiety/depression. Male and female patients and spouses,
however, did not differ in their symptoms of anxiety/depression, and young adult,
adolescent, and preadolescent children of these patients had differing results that were
influenced by characteristics such as age, sex, and whether it was their mother or father
who was ill. Although cancer patients, their spouses, and their children encountered
considerable stress at the time of diagnosis, this did not necessarily mean that the stress
they were encountering was occurring because of the people surrounding each person. It

could be that each person deals with stress and how it develops over time differently (Compas, et al., 1994).

For quality of life and mental health, we know that recurrence of cancer and whether a patient is undergoing treatment is associated with a cancer patient's physical state, whereas stage of cancer and patients' current social support network was associated with their mental state (see Parker et al., 2003). We also know that some type of mental stress does not occur because of the group of people surrounding a patient but because each patient processes events and deals with present stress differently than others (Compas, et al., 1994).

Family Functioning/Social Support

Another important thing to note is what factors exist in a social structure that help achieve the best results for the patient. For instance, variables such as ability to act openly and express feelings directly have been shown to be connected to lower levels of depression (Clarke & Edwards, 2004). A study by Kissane, Bloch, Burns, Patrick, Wallace, and McKenzie (1994) surveyed 40 to 65-year-old patients who had been identified as having one year or less of life expectancy and who had an adequate command of English, geographical accessibility, a living partner, and one or more children aged 12 or older (so that they could complete a set of questionnaires as well). The researchers used a series of questionnaires to separate 102 families into 5 definitive classes that related to each family's cohesiveness, conflict, and expressiveness. These classes included (a) supportiveness, (b) ability to resolve conflict, (c) hostility, (d) sullenness, and (e) ordinariness, which helped showcase what characteristics were most intense in each family. The researchers found that, overall, there is a correlation between

family functioning (i.e., communication and supportiveness) and the general psychological wellbeing of the patient (Kissane, et al., 1994). These results suggest that a positive relationship between adjustment to cancer and family functioning could be achieved if there was a more supportive atmosphere.

In addition to knowing that having a strong support system tends to improve the mental well-being of the patient, it is also important to know what factors have a possible correlation with a patient's attitude and adjustment to a cancer diagnosis. Research has shown that social support plays a significant role in health and well-being for patients (Cohen S. , Psychosocial models of the role of social support in the etiology of physical disease, 1988). In 1996, Cohen and Helgeson first reviewed a number of studies that focused on social support and the interactions that were the most beneficial for the patients, then manipulated certain aspects of the patient's social environment in order to determine the types of interactions that proved to be the most beneficial. They determined that emotional support was the type of support that cancer patients craved the most and associated best with adjustment to the disease, especially when the support came from someone who possessed great knowledge and insight into the patient's illness-related concerns. It was also stated, however, that to obtain the best results for adjustment in future research, educational interventions demonstrated more consistent positive results than did group/peer discussion interventions (Cohen & Helgeson, Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research, 1996). Educational interventions include providing information about cancer, cancer treatments, and how to manage the disease.

Although there is a relation between social support and the patient's mental health during treatment, it is also important to know how patients responded to the actual treatment as a function of their support system. DiMatteo (2004) completed a literature review of 122 studies and found a correlation between different types of social support (e.g. practical support, emotional support, unidimensional social support, family cohesiveness and family conflict, marital status, and living arrangement) and patient adherence to cancer treatment. Overall, patient adherence to cancer treatment showed positive trends in all areas, with functional measures of social support (e.g., practical, emotional, and family cohesiveness) correlating more strongly with adherence than structural measures of social support (e.g., marital status and living arrangement) (DiMatteo, 2004). Therefore, it was vital for patients to have a strong, supportive, and communicative environment, as this relates positively with their adherence to cancer treatment.

In terms of family functioning and social support, the most important findings to note are that (a) a supportive atmosphere can lead to better family functioning and better adjustment to cancer (Kissane, et al., 1994), (b) cancer patients responded better to educational interventions than they do to group or individual peer discussions (Cohen & Helgeson, Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research, 1996), and (c) having a supportive and communicative environment helps patients better respond to receiving treatment (DiMatteo, 2004).

Health Behavioral Changes

A patient's mental health is clearly important while adjusting to living with a disease such as cancer, but there is also the issue of cancer and cancer treatment(s) affecting the patient's physical health. Maintaining a healthy diet is crucial for the immune system, especially for cancer patients, so nutrition is a critical part of preserving immune responses (Chandra, 1997). A study by Humpel, Magee and Jones (2007) examined how a cancer diagnosis affected the health behaviors of cancer survivors, their family, and their friends. They recruited a total of 657 participants through multiple events that were endorsed by the Cancer Council Relay for Life. They used a questionnaire that included items such as age, gender, marital status, education, current employment status, physical activity levels, and changes in health behaviors, as well as the *Active Australia Survey* to measure physical activity levels. The researchers found that positive health changes were made for cancer survivors and their friends and family, including increased consumption of fruits and vegetables, decreased fat consumption, quitting smoking, and increased exercise. The authors concluded that a diagnosis may act as a 'cue to action' to improve health behaviors in cancer patients and those around them (Humpel et al. 2007), but this did not necessarily mean that this trend would occur for everyone.

A related question is whether positive health behaviors (e.g., absence of smoking, decrease in use of alcohol, more physical activity, etc.) are more prevalent in cancer survivors than in noncancer individuals. Bellizzi, Rowland, Jeffrey, and McNeel (2005) examined the prevalence of these health behaviors in both cancer survivors and individuals without a cancer diagnosis. They also questioned whether smoking, physical

activity, and alcohol prevalence differed by time since diagnosis, age of patient, and location of the cancer (i.e. breast, lung, prostate, etc.). This study used participants from the *National Health Interview Survey* (NHIS), which collects health-related data once a year from noninstitutionalized U.S. households. Overall, cancer survivors reported more positive health behaviors than did individuals who did not have cancer. About 20% of cancer survivors labelled themselves as current smokers, compared to 23.6% of those with no history of cancer. Cancer survivors also met physical activity recommendations more often than did individuals who did not have cancer, 36.6% and 29.6% respectively.

In terms of time since diagnosis, Bellizzi et al. (2005) also found that smoking use declined as the number of years since diagnosis increased, with similar results shown for meeting physical activity requirements. When comparing sites of cancer, breast, prostate, and colorectal cancer survivors had significantly lower levels of smoking than did lung, larynx, pharynx, and gynecological cancer survivors. Breast, prostate, and gynecological cancer survivors also reported meeting current physical activity recommendations more often than did survivors of cancer for the other sites. Age only seemed to play a significant role when considering the differences in health behaviors by cancer site (Bellizzi et al. 2005). Therefore, there seems to be a positive relation between cancer survivors and improving health behaviors, and time since diagnosis is the characteristic that shows the most positive correlation with improving health behaviors.

These results indicate that a cancer diagnosis could act almost as a 'cue to action' to improve health behaviors in cancer patients/survivors, their families, and their friends. Cancer survivors tended to report more positive health behaviors than people with no history of cancer in their families (Bellizzi et al., 2005).

Summary and Rationale for the Present Study

Certain factors have been identified as relating to a cancer patient's physical and mental state. Having a strong support network is correlated with positive changes in areas such as communication, adjustment to cancer, and adherence to treatment (DiMatteo, 2004; Helgeson & Cohen, 1996; Kissane, et al., 1994). Research has also shown that receiving a cancer diagnosis can act as a teachable moment for cancer patients/survivors and their friends and family to begin making positive health behavioral changes (Humpel et al. 2007). Although it has been shown that having a strong social support network helps improve a person's mental health and adjustment to cancer (DiMatteo, 2004; Parker et al. 2003), it isn't known what measures are actually taken within the social support network to help create a more supportive and communicative atmosphere. The present research examined the relation between mental, physical, and emotional changes that cancer survivors believed may have occurred over the course of their treatment and how their family's involvement played a role in those changes. Also, instead of just confirming that emotional support helps better the quality of life and mental health of the patient, the present study specifically asked participants to identify whether specific support measures existed in their support group while they were undergoing treatment and the extent to which those support measures helped.

Research has also shown that positive health behavioral changes occur not only in cancer patients/survivors, but also in their families and friends; however, although specific examples of these health behavioral changes have been identified, it is not known if and/or how the cancer patient's/survivor's support network encouraged them to make these changes. The current study attempted to identify specific examples of family

support by asking survivors to identify which support measures they experienced and found helpful.

In this study, participants completed an online survey consisting of questions about (a) their health concerns during treatment, (b) the quality of their family relationships during treatment, (c) their adjustment to their cancer diagnosis, (d) perceived change in their social, emotional, and physical, and functional well-being during treatment, and (e) their perceptions of family involvement and support during treatment. The survey consisted of questions from (a) an adapted version of the *Functional Assessment of Cancer Therapy-General* (FACT-G) (Cella, 1993), (b) the *Cancer Worry Scale* (CWS) (Custers, et al., 2014), (c) the *Family Assessment Device* (FAD) (Epstein, Baldwin, & Bishop, 1983), (d) the *Impact of Event Scale* (IES) (Horowitz, Wilner, & Alvarez, 1979), (e) the *General Health Questionnaire* (GHQ) (Goldberg & Hillier, 1979), as well as (f) family support and (g) family perspective questions and additional demographic questions.

The following hypotheses were made:

1. Having a strong family support network (as measured by the FAD) would be positively correlated with areas such as communication (as measured by the FACT-G social and family support questions) and adjustment to cancer (as measured by the FACT-G functional and the IES).

2. Strong communication within the family (as measured by the FACT-G social and family support questions) would also be correlated with fewer reported anxiety/depression symptoms during treatment (as measured by the FACT-G

emotional, GHQ, & family perspective questions), as well as higher levels of problem-solving within the family unit (as measured by the FAD).

3. Greater family involvement in dietary/physical activity changes (as measured by the family support and family perspective questions) would be correlated with more positive outcomes in health behaviors such as improved diet and increased physical activity (as measured by the FACT-G physical and GHQ).

4. Emotional support (as measured by the family support-emotional questions) would be rated as more beneficial than behavioral support (as measured by the family support-behavioral questions).

CHAPTER II

Methods

Participants

The participants were 22 cancer survivors. For purposes of this study, a "survivor" was defined as someone who had been post-active treatment for at least one year. The participants consisted of 19 females and 3 males from various educational, marital, and working backgrounds. Fifteen participants had breast cancer, one had colon cancer, one had skin cancer, one had prostate cancer, and the remaining seven were treated for other types of cancer. There was a total of 16 participants excluded from the survey for various reasons including (a) not agreeing to the terms and conditions, (b) not answering vital questions, and/or (c) not meeting the necessary requirements for inclusion in this study. See Table 1 for more extensive sample demographic characteristics.

Materials

Demographic questions assessed sex, age, ethnicity, education, work status, type of cancer, length of time in treatment, length of time in remission, and number and age of children living and not living at home during treatment. Demographic questions can be found in Appendix A.

The *Functional Assessment Cancer Therapy – General* (FACT-G) (Cella, 1993) is used with cancer patients to assess their previous seven days but was adapted in the present study to ask cancer survivors about their time undergoing treatment; wording was changed from present tense to past tense. The scale is comprised of 27 questions, divided into 4 categories: (a) physical well-being (e.g., "I had nausea."); (b) social/family well-being (e.g., "I got emotional support from my family."); (c) emotional well-being (e.g., "I

12

Table 1:

Sample Demographic Characteristics

	Frequency
Gender	
Male	3
Female	19
Ethnicity	
White	21
American Indian or Alaska Native	1
Marital Status	
Married	18
Divorced	3
Widowed	1
Employment	
Full-time	12
Part-time	1
Retired	6
Unemployed	3
Education	
High school	2
Some college	6
Associate's	1
Bachelor's	5
Master's	5
Doctorate/PhD	3
Type of Cancer	
Breast	12
Colon	1
Skin	1
Prostate	1
Other	7
Treatment Received	
Chemotherapy	13
Radiation	13
Surgery	15

Table 1 (continued):

Sample Demographic Characteristics

Length of Time in Treatment	
< 6 months	6
6 mo. - 2 yr.	11
2 yr. - 5 yr.	3
5 yr. - 10 yr.	1
> 10 yr.	0
Length of Time Post-Active Treatment	
< 6 months	3
6 mo. - 2 yr.	1
2 yr. - 5 yr.	6
5 yr. - 10 yr.	5
> 10 yr.	4
How long have you been off of any medication relating to your illness?	
< 6 months	3
6 mo. - 2 yr.	2
2 yr. - 5 yr.	4
5 yr. - 10 yr.	8
> 10 yr.	4
How many children were living at home during your treatment?	
0	10
1	5
2	7
How many children were not living at home during your treatment?	
0	11
1	5
2	5
3	1

felt sad."); and (d) functional well-being (e.g., "I was able to enjoy life."). Questions are scored on a scale of 0 = *not at all* to 4 = *very much*. Separate scores are derived for each category; higher scores for physical well-being and emotional well-being suggest poorer well-being, and higher scores for functional well-being and social/family well-being suggest more adaptive well-being. Scores on questions from the physical well-being and emotional well-being categories were reverse-scored for analysis. Questions can be found in Appendix B.

The Cancer Worry Scale (CWS) (Custers, et al., 2014) has eight questions that assesses survivors' fears and concerns of recurrence of cancer. Items are scored on a 5-point scale, from 0 = *not at all* to 4 = *very often/very much*. For the current study, only the first six questions were used, and question wording was changed from present tense to past tense. Higher scores suggest the patient felt a great deal of fear and concern of recurrence of cancer. Questions can be found in Appendix C.

The Family Assessment Device (FAD) (Epstein et al., 1983), assesses the status of a survivor's relationship with his or her family. The entire scale consists of 60 questions scored on a 5-point scale, from 1 = *strongly agree* to 5 = *strongly disagree*. Questions are divided into six categories in the survey: (a) problem solving; (b) communication; (c) roles; (d) effective responsiveness;(e) effective involvement; and (f) behavior control. Higher scores are suggestive of greater family dysfunction. For the current study, question wording was changed from present tense to past tense. The following 18 questions from this scale were used in the present study: 3, 6, 7, 9, 11, 14, 18, 21, 26, 28, 38, 46, 49-50, 56-57, and 59-60. These questions were selected over the others because of

their ability to address communication in the household for the present study. Questions can be found in Appendix D.

The *Impact of Event Scale* (Horowitz et al., 1979), asks survivors how they feel about a traumatic event, which in this case was the cancer diagnosis and treatment. This scale consists of 20 items divided into 4 clusters; however, only 6 questions were used from this scale: (a) Cluster 1: questions 1 and 6; (b) Cluster 2: question 1-2 and 4; and (c) Cluster 3: question 2. These questions were selected over the others for their ability to address how the survivor processed their treatment while it was occurring. Items were scored on a 4-point frequency scale, from 0=*never* to 3=*often.* Questions can be found in Appendix E.

The *General Health Questionnaire* (GAD) (Goldberg & Hillier, 1979) is used to help detect diagnosable psychiatric disorders. Twenty-eight questions are designed to focus on four different categories: (a) somatic symptoms; (b) anxiety and insomnia; (c) social dysfunction; and (d) severe depression. Two questions were used from category A, three questions from category B, three question from category C, and one question from category D. These questions were selected to assess how a patient felt while undergoing treatment. Items are scored on a 4-point scale, from 1 = *never* to 4 = *often*. For the current study, question wording was changed from present tense to past tense. Questions from this scale can be found in Appendix F.

Eleven additional family support questions were developed for use to assess the participants' views of their families' emotional and behavioral support during treatment. Questions were scored on a 5-point scale, from 1 = *strongly disagree* to 5 = *strongly agree*. For each of these questions, individuals also rated how beneficial they viewed that

support on a scale of 1= *not at all beneficial* to 5= *definitely beneficial.* Higher scores

suggested higher family support and greater perceived benefits. Questions can be found

in Appendix G.

Three questions also were developed to assess family perspective. Participants

rated the extent to which they believed their families' think they changed cognitively,

physically, and emotionally as a function of treatment. Questions are scored on a 5-point

scale, from 1 = *not at all* to 5 = *a great deal.* Questions can be found in Appendix H.

Procedure

Data was collected through the course of a survey that was disseminated

throughout multiple cancer support groups and throughout social media/survey websites

that would specifically be sent to cancer support groups. IRB approval was secured

before any data was collected. The approval letter is included at the back of this paper.

Participants completed an online survey through Qualtrics that consisted of questions

from the surveys. It generally took participants 10-15 minutes to complete the entire

survey.

After a certain time period of attempting to reach the desired number of

participants, surveying was closed, and the obtained results were imported to the SPSS

program. Once we were finished importing, we removed the surveys where participants

did not (a) properly give consent and were not granted access to the full survey or (b) did

not answer question(s) that were required for data collection, making their data unusable.

CHAPTER III

Results

The first hypothesis was that having a strong family support network (as measured by the FAD) would be positively correlated with areas such as communication (as measured by the FACT-G social and family support questions) and adjustment to cancer (as measured by the FACT-G functional and the IES). The FAD score was not correlated with scores on the FACT-G social, $p = .223$, the FACT-G functional, $p = .395$, the IES, $p = .903$, or the family support-behavior questions, $p = .260$. Thus, there were no significant correlations between having a strong family network and the ability to communicate and adjust to cancer, using these measures.

The second hypothesis was that strong communication within the family (as measured by the FACT-G social and family support questions) would also be correlated with fewer reported anxiety/depression symptoms during treatment (as measured by the FACT-G emotional, GHQ, & family perspective questions), as well as higher levels of problem-solving within the family unit (as measured by the FAD). FACT-G social scores were significantly negatively correlated with scores on both the FACT-G emotional, r $(16) = -.600$, $p = 0.011$, and the family perspective questions, r $(14) = -.536$, $p = .039$. FACT-G social scores were not, however, correlated with scores on the GHQ, $p = 0.066$, or with scores on the FAD, $p = .223$. Family support-behavior scores were also not correlated with scores on the FACT-G emotional, $p = .107$, scores on the GHQ, $p = .631$, scores on the FAD, $p = .260$, or on scores for the family perspective questions, $p = .077$. Hence, in only one situation did participants report a relation between their families'

ability to communicate and their decreased mental health troubles. No relations were found between family communication and participants' ability to solve problems.

The third hypothesis was that greater family involvement in dietary/physical activity changes (as measured by the family support-behavior and family perspective questions) would be correlated with more positive outcomes in health behaviors such as improved diet and increased physical activity (as measured by the FACT-G physical and GHQ). Family support-behavior scores were not correlated with scores on either the FACT-G physical, $p = .882$, or the GHQ, $p = .879$. Family perspective scores, however, were positively correlated with scores on the FACT-G physical subscale, $r(21) = .483$, $p = .031$, but were negatively correlated with scores on the GHQ, $r(16) = -.642$, p = .005. Accordingly, there was a relation between participants' reports that their families believed that they changed and actual change in their physical behaviors and dietary commitments. This did not extend to participants' reports of general health.

The fourth hypothesis was that emotional support (as measured by the family support-emotional questions) would be rated as more beneficial than behavioral support (as measured by the family support-behavioral questions). Participants did not rate emotional support ($M = 2.600$) as more beneficial than behavioral support ($M = 2.716$), $t(13) = -.648$, $p = .528$. There was, however, a positive correlation between the scores on the family support-emotional and the family support-behavioral questions, $r(14) = .795$, $p = .000$; so, participants who reported that their families were high in emotional support also reported that their families were high in behavioral support.

CHAPTER IV

Discussion

The primary purpose of this study was to examine whether certain positive behaviors exhibited by cancer patients were positively related with patient's perceptions of family involvement, as well as whether some types of support were more beneficial than others.

The findings from the research concluded that, although some areas had results in the expected direction according to our hypotheses, in most cases, participants' responses did not indicate relations between their experiences with cancer and their families' support. The first hypothesis showed no indication of a relation between having a strong family network and the ability to communicate and adjust to cancer. The second hypothesis showed that although there was a relation between their families' ability to communicate and decreased mental health problems, there was no relation between ability to communicate and increased problem-solving. The third hypothesis reported that when the participants' families believed they changed their dietary and physical habits, there was an actual change in physical activity and dietary commitments. Finally, the fourth hypothesis showed that participants did not report that emotional support was more beneficial than behavior support. Families who were high in emotional support were also high in behavioral support.

It was surprising that in most cases, the hypotheses were not supported. For example, Kissane's research (1994) found that a supportive atmosphere could lead to better family functioning, and Helgeson's study (1996) found that a supportive atmosphere could lead to better adjustment to cancer. In the present study, there were no

significant correlations between supportive atmosphere, better family functioning, and experiences with cancer. However, this could be due to the difference in how variables were measured. For instance, Kissane used the *Family Environment Scale* (FES), whereas this project used numerous other surveys to measure family functioning including the *Functional Assessment Cancer Therapy – General* (FACT-G) (Cella, 1993) and the *Family Assessment Device* (FAD) (Epstein et al., 1983). The FACT-G and the FAD were used because of their specificity to families undergoing cancer treatments as well as understanding how they communicated during that period while the FES is focused more on a general home environment as well as categorizing families based on factors such as alcohol, asthma, bereaved, and divorced.

A study by Compas et al. (1994) examined whether or not certain factors including gender, stage and type of cancer contributed to the mental well-being of a cancer patient/survivor, and it was concluded that although these factors can affect a person's well-being, the people surrounding them is not one of those features. These results are similar to those found in the present study, where there was only one instance in which the families' increase ability to communicate was related to participants decreased mental health problems. The results for our study versus Compas et al. (1994) could have differed due to the fact that different scales were used in each study, as well as the fact that children were surveyed in the study done by Compas et al.

Humpel et al. (2007) examined whether or not a cancer diagnosis affected the health behaviors of cancer survivors, their family, and their friends. They determined that a cancer diagnosis encouraged more positive health behaviors from the survivors as well as their family and friends, and noted that those whose families' participated were more

consistent with their diet. The present study also showed that there was a significant correlation between family involvement and consistent dietary changes among cancer survivors. Finally, Cohen (1988) concluded much the same way as Kissane (1994) furthering the conclusion that family involvement does play a significant role on consistent dietary changes among cancer survivors.

Limitations of Present Study

One obvious limitation of the present study is sample size. The proposal called for the number of participants for this research project to be 50. Due to the specificity of the requirements needed in order to participate in the survey, finding an appropriate number of participants was somewhat challenging. The requirements included a) being 18 years old or older and b) having been post-cancer treatment for over a year. This means that anyone attending regular doctor's appointments, receiving treatment, and/or taking medication was not allowed to participate in the survey. The specificity of the requirements for participants also made it difficult to find people who fit into that specific category. Numerous cancer support groups in the Nashville and Atlanta area were contacted for participant recruitment, but Gilda's Club in Nashville is the only group that had a regular support group and Facebook page for our survey to be disseminated.

Another limitation of the present study was that after being contacted by a few of the participants, it was noted that the wording of the questions could have been considered confusing. For example, one of the blocks of questions had paired answers, i.e. strongly agree; not at all beneficial. This means that each choice could have had one of two answers depending on the question that was asked in the survey. This caused numerous participants who had answered the majority of the survey to later be excluded

due to the fact that they had not answered an entire block of questions that was vital for analysis. It is also possible that this style of questioning led to many people answering at the opposite end of the spectrum to what they should have because they believed one option of the answer was supposed to be used when, in fact, it was supposed to be the opposing answer.

Future Directions

In the future, I would like to focus more on one area of questioning rather than trying to cover a litany of areas within cancer treatment and family functioning. For example, I would focus solely on communication between the cancer patients/survivors and their family and friends rather than trying to cover communication, problem-solving, and mental and physical well-being. I have also considered the possibility of taking surveys from the family members of cancer survivors and/or people who passed away from cancer. It was discussed before data collection began that the cancer survivor's perspective of the situation could be skewed due to a few obstructions such as treatments, drugs, etc. Family members of cancer patients/survivors will never truly know the hardships that survivors go through, but as they do not undergo vigorous treatment and do not experience inhibitions from surgeries, treatments, medications, etc., they could give a more clear perspective of how the cancer patient/survivor behaved during that time period.

In summary, the results from the present study suggests that strong family support and involvement can be helpful in areas such as decreasing mental health problems, increasing physical activity and better dietary choices, but that it is not significantly related to communication, adjustment to cancer, and problem-solving. This also reports a

need for further inquiry to determine whether these results would be consistent among

groups outside of the participants, including their families. Family members could bring a

different perspective of how the family dealt with the stress of a cancer diagnosis, levels

of communication, and whether emotional and behavioral support were more beneficial.

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APPENDICES

Appendix A

Demographic Questions

1. Age: _____

2. Gender:

   □Male

   □Female

3. Ethnicity:

   □White

   □Black/African American

   □American Indian

   □Asian Indian

   □Asian

   □Latino

   □Other (please list): _____

4. Marital Status during Cancer Treatment:

   □Single

   □Partnership

   □Married

   □Divorced

   □Widowed

5. Work Status during Cancer Treatment:

    □Student

    □Full-time

    □Part-time

    □Retired

    □Unemployed

6. Education:

    □Some high school

    □High school diploma

    □Some college

    □Associate Degree

    □Bachelor's Degree

    □Master's Degree

    □Doctorate/PhD

    □Other (please list): _____

7. Type of cancer:

        ☐Breast

        ☐Kidney

        ☐Lung

        ☐Colon

        ☐Skin

        ☐Prostate

        ☐Ovarian

        ☐Other (please list): _____

8. Type of Treatment Received:

        ☐Chemotherapy

        ☐Radiation

        ☐Surgery

9. Length of time in treatment:

        Years: _____

        Months: _____

        If you received treatment more than once, list time here: _____

10. Length of time in remission:

        Years: _____

        Months: _____

        If you have been in remission more than once, list time here: _____

11. How long have you been off any medication relating to your illness? _____

12. How many children were living at home during your treatment?

_____

13. How many children were not living at home during your treatment?

_____

Appendix B

Functional Assessment of Cancer Therapy-General (FACT-G) Questions

Emotional Well-Being

1. I felt sad.

2. I was satisfied with how I coped with my illness.

3. I lost hope in the fight against my illness.

4. I felt nervous.

5. I worried about dying.

6. I worried that my condition would get worse.

Functional Well-Being

1. I was able to work (include work at home).

2. My work (include work at home) was fulfilling.

3. I was able to enjoy life.

4. I had accepted my illness.

5. I slept well.

6. I enjoyed the things I usually did for fun.

7. I was content with the quality of my life.

Physical Well-Being

1. I had a lack of energy.

2. I had nausea.

3. Because of my physical condition, I had trouble meeting the needs of my family.

4. I had pain.

5. I was bothered by side effects of treatment.

6. I felt ill.

7. I was forced to spend time in bed.

Social/Family Well-Being

1. I felt close to my friends.

2. I got emotional support from my family.

3. I got support from my friends.

4. My family accepted my illness.

5. I was satisfied with family communication about my illness.

6. I felt close to my partner (or the person who was my main support).

7. I was satisfied with my sex life.

Scoring

0 = *Not at all*

1 = *Very little*

2 = *Sometimes*

3 = *Often*

4 = *Very much*

Appendix C

Cancer Worry Scale (CWS) Questions

1. How often did you think about your chances of getting cancer (again)?

2. How often did those thoughts affect your mood?

3. How often did these thoughts interfere with your ability to do your daily activities?

4. How concerned were you about the possibility of getting cancer (again) one day?

5. How often did you worry about developing cancer (again)?

6. How much of a problem was this worry?

Scoring

0 = *Not at all*

1 = *Very little*

2 = *Sometimes*

3 = *Often*

4 = *Very much/often*

Appendix D

Family Assessment Device (FAD) Questions

1. When someone was upset the others knew why. (Question 3)

2. In times of crisis we could turn to each other for support. (Question 6)

3. We didn't know what to do when an emergency came up. (Question 7)

4. We were reluctant to show our affection for each other. (Question 9)

5. We could not talk to each other about the sadness we felt. (Question 11)

6. You couldn't tell how a person was feeling from what they were saying. (Question 14)

7. People came right out and said things instead of hinting at them. (Question 18)

8. We avoided discussing our fears and concerns. (Question 21)

9. We could express feelings to each other. (Question 26)

10. We did not show our love for each other. (Question 28)

11. We resolved most emotional upsets that came up. (Question 38)

12. We were able to make decisions about how to solve problems. (Question 46)

13. We expressed tenderness. (Question 49)

14. We confronted problems involving feelings. (Question 50)

15. We confided in each other. (Question 56)

16. We cried openly. (Question 57)

17. When we didn't like what someone had done, we told them. (Question 59).

18. We tried to think of different ways to solve problems. (Question 60)

Scoring

1 = *Strongly agree*

2 = *Somewhat agree*

3 = *Neither agree nor disagree*

4 = *Somewhat disagree*

5 = *Strongly disagree*

Appendix E

Impact of Event Scale (IES) Questions

1. I had waves of strong feelings about it. (Cluster 1 Question 1)

2. I had difficulty falling asleep because of images or thoughts related to the event.

   (Cluster 1 Question 6)

3. I knew that a lot of unresolved feelings were still there, but I kept them under wraps.

   (Cluster 2 Question 1)

4. I avoided letting myself get emotional when I thought about it or was reminded of it.

   (Cluster 2 Question 2)

5. I made an effort to avoid talking about it. (Cluster 2 Question 4)

6. I used alcohol, drugs, or a lot of activity to help me forget. (Cluster 3 Question 3)

Scoring

0 = *Never*

1 = *Rarely*

2 = *Sometimes*

3 = *Often*

Appendix F

General Health Questionnaire (GHQ) Questions

1. Felt perfectly well and in good health? (Question A1)

2. Felt run down and out of sorts? (Question A3)

3. Lost much sleep over worry? (Question B1)

4. Felt edgy and bad-tempered? (Question B4)

5. Felt nervous and strung-up all the time? (Question B7)

6. Managed to keep yourself busy and occupied? (Question C1)

7. Felt that you were playing a useful part in things? (Question C5)

8. Was able to enjoy your normal day-to-day activities? (Question C7)

9. Found at times you couldn't do anything because your nerves were too bad?

   (Question D5)

Scoring

1 = *Never*

2 = *Rarely*

3 = *Sometimes*

4 = *Often*

Appendix G

Family Support Questions

1.   My family let me know they cared about my well-being (emotional).

How beneficial did you find this support?

2.   My family let me know they cared about my opinions about treatment

(emotional).

How beneficial did you find this support?

3.   My family gave me any privacy I needed (emotional).

How beneficial did you find this support?

4.   I was always included in decisions that regarded family matters (emotional).

How beneficial did you find this support?

5.   My family listened, even when I did not expect responses (emotional).

How beneficial did you find this support?

6.   My family was respectful of me, even during bad days (emotional).

How beneficial did you find this support?

7.   My relationship with my family did not change much after receiving the diagnosis

(emotional).

How beneficial did you find this support?

8.   My family always offered assistance, even when it was not expected (behavioral).

How beneficial did you find this support?

9.   My family participated in any dietary changes I had to make while I was

undergoing treatment (behavioral).

How beneficial did you find this support?

10. My family participated in any physical activity changes I had to partake in while I was undergoing treatment (behavioral).

How beneficial did you find this support?

11. My family attended doctor's appointments, treatment sessions, and hospitalizations (behavioral).

How beneficial did you find this support?

Scoring

1 = *Strongly disagree; not at all beneficial*

2 = *Somewhat agree; rarely beneficial*

3 = *Neither agree nor disagree; sometimes beneficial*

4 = *Somewhat disagree; beneficial*

5 = *Strongly disagree; definitely beneficial*

Appendix H

Family Perspective Questions

1. My family believes I changed cognitively while undergoing treatment (e.g.,

memory problems, took longer to solve problems, took longer to find the right words).

2. My family believes I changed physically while undergoing treatment (e.g.,

gained/lost weight, increased/decreased physical activity, etc.).

3. My family believes I changed emotionally while undergoing treatment (e.g., more

depressed, more anxious, more irritable).

Scoring

1 = *Not at all*

2 = *A little*

3 = *Somewhat*

4 = *Much*

5 = *A great deal*

IRB Approval Letter

IRB
INSTITUTIONAL REVIEW BOARD
Office of Research Compliance,
010A Sam Ingram Building,
2269 Middle Tennessee Blvd
Murfreesboro, TN 37129

MIDDLE TENNESSEE STATE UNIVERSITY

IRBN007 – EXEMPTION DETERMINATION NOTICE

Monday, November 05, 2018

Principal Investigator	**Sunny Lusins** (Student)
Faculty Advisor	Michelle Boyer-Pennington
Co-Investigators	NONE
Investigator Email(s)	*sbl3c@mtmail.mtsu.edu; michelle.boyer-pennington@mtsu.edu*
Department	Psychology

Protocol Title	***Perceptions of family support in cancer survivors***
Protocol ID	**19-1033**

Dear Investigator(s),

The above identified research proposal has been reviewed by the MTSU Institutional Review Board (IRB) through the **EXEMPT** review mechanism under 45 CFR 46.101(b)(2) within the research category *(2) Educational Tests* A summary of the IRB action and other particulars in regard to this protocol application is tabulated as shown below:

IRB Action	**EXEMPT from furhter IRB review*****	Date	**11/5/18**
Date of Expiration	NOT APPLICABLE		
Sample Size	100 (ONE HUNDRED)		
Participant Pool	**Healthy Adults (18 or older)**		
Exceptions	Online consent and data collection are permitted		
Mandatory Restrictions	1. Participants must be 18 years or older 2. Informed consent must be obtained from the participants 3. Identifying information must not be collected		
Restrictions	**All restrictions for exemption apply.**		
Comments	NONE		

***This exemption determination only allows above defined protocol from further IRB review such as continuing review. However, the following post-approval requirements still apply:

- Addition/removal of subject population should not be implemented without IRB approval
- Change in investigators must be notified and approved
- Modifications to procedures must be clearly articulated in an addendum request and the proposed changes must not be incorporated without an approval
- Be advised that the proposed change must comply within the requirements for exemption
- Changes to the research location must be approved – appropriate permission letter(s) from external institutions must accompany the addendum request form
- Changes to funding source must be notified via email (irb_submissions@mtsu.edu)
- The exemption does not expire as long as the protocol is in good standing
- Project completion must be reported via email (irb_submissions@mtsu.edu)
- Research-related injuries to the participants and other events must be reported within 48 hours of such events to compliance@mtsu.edu