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Running head: PATIENT ADVOCACY

The Effect of Patient Advocacy on Cancer Patients' Fear and Anxiety Levels

A Thesis Presented to The Faculty of the Department of Communication

Rochester Institute of Technology

In Partial Fulfillment of the Master of Science Degree in

Communication & Media Technologies

by

Joan Clancy Vezelis

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I would like to thank Rudy Pugliese for his continuous support from the day he coerced me into this discipline. To Nicole Trabold whom I will admire forever, and my stepmother Judy Clancy, for always believing in me and literally pushing me onto the next level in my life.

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Abstract

Healthcare outcomes may be adversely affected by patients' fear and anxiety associated with communication with health care providers. The present study investigated whether patient advocates can affect levels of fear and anxiety in hospitalized patients as measured by the Personal Report of Communication Apprehension scale (PRCA-24), the Hospital Anxiety and Depression Scale (HADS), and the Child Surgery Worries questionnaire (CSW). Decreases were found on all three scales subsequent to patient interaction with a patient advocate. Implications and future research are discussed.

In 2004, more than a half million Americans died of cancer, a rate of more than 1500 people a day with an estimated 699,560 men and 668,470 women afflicted with cancer in the United States alone (American Cancer Society, 2004). The American Cancer Society (2004) estimates that one in two people will get some form of cancer in their lifetime. The fear and anxiety that accompany this disease test a person's inner strength and leave many questioning if they are up to the fight of their life. The psychological fears felt by cancer patients may inhibit their interpersonal communication with healthcare providers and negatively affect healthcare outcomes such as the emotional response to their diagnosis, physical response to treatment, and satisfaction with their healthcare team. Patient advocates attempt to address these outcomes by identifying communication problems with their healthcare team and acknowledging patients' affective and cognitive needs during their hospitalization.

Patient advocacy has been an important part of the healthcare field for many years serving patients in all different areas of the healthcare system. Some people believe patient advocacy stemmed from Florence Nightingale's concern that the world was a harsh, cruel place and that patients need protection (Nelson, 1988). Others believe that the Bill of Human Rights was the beginning of patient rights and advocacy (Mallik & McHale, 1995). The earliest information regarding patient advocates suggests that they support patients in decisions, provide facts about their healthcare situation, and explain their rights as patients, essentially providing the link between healthcare providers and patients (Bosek, 2003).

The concept of serving as a patient advocate has evolved over the past 20 years. Many healthcare institutions have policies (proscribed by law) on how to provide a surrogate decision maker for a patient who cannot do so. For example, if in-patients ask the hospital to have someone advocate for them personally because they do not feel they are receiving adequate treatment, the hospital may assign a nurse case manager, ethics consultant, or someone from the patient relations department. Unfortunately, policies for identifying patient advocates for patients are far less common. Presently, many hospitals do not have standard procedures in place, such as written instructions on when to ask for the assistance of a patient advocate or who would be the best person to fulfill this role (Bosek, 2003).

While hospitals are trying to determine patient needs and assign appropriate people to advocate for them, patient advocate groups in local communities across the country are becoming vital resources for people with various illnesses. There are many types of patient advocate groups that already exist. The main goals of these groups are to raise awareness of specific healthcare issues and to make them national priorities while keeping the individual with the illness the main priority. These groups try to provide emotional support, information about procedures the person may have to endure, and answers to any questions the patient may have (Carroll, 2004).

Patient advocate groups aim to involve patients and families to help make a difference nationwide. They do this by introducing research and patient care plans as well as services to people with certain diseases. For example, in 1997 a prostate cancer advocacy group was responsible for implementing at least 25 new patient-centered

initiatives according to a recent research study (Carroll, 2004). Patient-centered services put to use include packets of valuable information to prostate cancer patients, publications posted on various cancer Websites including educational pieces for newly diagnosed patients, and the introduction of nutritionists specifically trained in the dietary needs of people with prostate cancer. These services provide examples of advocacy because they put the needs of the patient first, thus making people publicly aware of the disease and providing them with necessary information.

Interpersonal communication

According to Fellowes, Wilkinson, and Moore (2005) high quality health care is achieved when open communication between healthcare providers and patients are present. Fallowfield (1998) reports that bad communication can result in greater chances of malpractice, recovery time taking longer than expected as well as wrong clinical reports. For physicians, a lack of communication training can result in problems with their patients leading to an elevation in career stress, burnout levels and decreased job satisfaction.

There is a misconception that cancer patients would rather have an expert in the healthcare field rather than someone they would feel comfortable communicating with on an interpersonal level (Fallowfield, 1995). Although physicians are considered to be experts in the healthcare field, they are not in the area of communications. This may cause the patients to distance themselves and avoid discussing their feelings.

This missing link in the healthcare provider-patient relationship can result in patients feeling anxious, fearful and not cared for, while healthcare providers experience

burnout, low moral and increased job stress. A bridge is needed to connect these two parties to improve outcomes for both sides.

Fear in cancer patients

Fear is one of the most prominent emotions of a person diagnosed with cancer (Holland & Louis, 1999). Fear of dying as well as the fear of treatment can become quite overwhelming. Lee-Jones (1997) concluded that the psychosocial and psychological needs of cancer patients are often overlooked. It has been found that cancer patients are hesitant to talk with their healthcare providers about symptoms of depression and that this may be due to doctors believing that this behavior is part of the cancer diagnosis (Williams & Gossett, 2001). Not only does fear attend the diagnosis of cancer, but patients are afraid to discuss symptoms of depression with their doctors. Common fears felt by cancer patients include money, family, career, and their cancer spreading without their knowledge. Once the patient has been treated and considered in remission, a daunting question they ask themselves is will it come back?

Fear of reoccurrences of cancer in patients has been shown to be significant for many cancer patients (Lee-Jones, 1997). Wong and Bramwell (1992) investigated the relationship between uncertainty and anxiety in patients following a mastectomy. The study reports that 48% of participants expressed uncertainty, while 88% expressed some form of anxiety. These findings suggest that patients who are uncertain about their illness suffer from anxiety as well. Therefore, it could be argued that mastectomy patients who worry about their cancer returning suffer from anxiety and could benefit from the help of a patient advocate while communicating with healthcare providers.

Another study looked at the fear of reoccurrence in mastectomy patients. In a study of 269 women, 61 had a reoccurrence and 38 were interviewed to determine their emotional state (Hall, Fallowfield & A'hern, 1996). Half of these women were found to be clinically depressed, anxious, or both. A big concern of 30 of these women was that they felt they did not receive any support from their hospital following the discovery of the cancer returning. This is consistent with the data inferring that a lack of communication with cancer patients can lead to feelings of anxiety, which may result in patient dissatisfaction (Skarstein, Dahl, Laading & Fossa, 2002).

Patient Satisfaction

A patient satisfaction study conducted at an oncology clinic showed a direct relation between physician's attentiveness and empathy to patients' feelings of distress and satisfaction (Zachariae, Pedersen, Jensen, Ehrnrooth, Rossen, & von der Masse, 2003). Physicians who had less empathy were also less likely to determine when their patients were satisfied with their care. Patient dissatisfaction has been found to result in poor compliance, longer recovery time and less recall of information. This lack of information commonly leads to anxiety and uncertainty regarding the patient's disease. On the other hand, satisfied patients are more likely to complete their treatment, create a follow up plan and communicate more effectively with their physician (Skarstein et al., 2002).

In a recent study of women with breast cancer, 61% said they were highly dissatisfied with how they were told of their diagnosis and that this made them very angry (Turner, Kelly, Swanson, Allison & Wetzig, 2005). In another recent study done on

allogenic bone marrow patients (one of the most stressful treatments in cancer care today) it was found that the communication of their diagnosis by their doctor was extremely stressful. This study emphasized the need for improvement in patient-physician communication (Heinonen, Volin, Zevon, Uutela, Barrick, & Ruutu, 2005). The diagnosis of cancer is a life-changing event in a person's life. Patients' health depends on their ability to express their fears and anxieties regarding this disease so they can concentrate on achieving a positive outcome.

Taking on the role of a patient advocate:

A number of professionals have acted as patient advocates such as nurse case managers, physicians and ethic consultants. Nurses advocate for the patient, physicians try to prolong life, and ethic consultants aim to protect patient rights (Hayden, 1999).

A 2001 nursing communication research study (Williams & Gossett, 2001) suggests that a major role of the nurses is to mediate and clarify communications between patients and their physicians. Two themes surfaced from this study: The most common theme was the nurse making sure the patient understood what the physician told them (present in 73 of 86 interviews). The second most common theme was the nurse encouraging the patient to speak with the physician further, to clarify uncertainties regarding procedures (present in 62 out of 86 interviews). The role of the nurse in this study was to intervene and increase communication between patient and physician.

Nurse case managers are registered nurses with masters degrees in social work. In a qualitative analysis of nurse case managers and their role as patient advocates five themes emerged from in-depth interviews: 1) the struggle between empowering the

patient and taking the directive approach, which is deciding what is best for the patient; 2) the process of advocacy, which involves knowing their way around the healthcare system, providing quality care, educating the family, and going above and beyond for the patient; 3) clinical knowledge of the case manager, the use of the resources available, the importance of building relationships, and having tenacity and organizational skills; 4) barriers advocates are faced with such as time constraints and doing more with less; and 5) advocacy facilitators working as a team and having rapport with insurance companies. These five themes represent all the areas where advocates are needed. For example, deciding when a patient needs help making decisions, the importance of navigating through the healthcare system, and problems of not having enough time to spend with patients. It has become clear how patient advocates can benefit the healthcare field.

Nurse case managers take on different roles at different hospitals (Hellwig, Yam, & DiGiulio, 2003). For example, in one hospital they may work in the management of clinical protocols for patients with specific diagnoses. At another hospital they may only work to ensure quality care and services to the patients. This demonstrates an inconsistency in the role of the nurse case manager as a patient advocate. Patients need and deserve to know that at any hospital in which they are admitted, a patient advocate will be the same patient-centered employee they can depend on. The values expressed by the nurse case managers in this study such as being relationship-focused, credible, and able to work effectively with physicians and other healthcare workers create a good starting point for the emerging field of patient advocacy.

Other employees in the healthcare field can take on the role of a patient advocate. Nelson (2003) reports that the role of an ethics consultant is to resolve conflicts with particular attention to the responsibilities, rights and interests of the parties involved. In “The Case of Ms. M,” (Nelson, 2003) an ethics consultant was called to advocate for a patient. The patient had a previous relationship with the head of the ethics department. Because the hospital did not have a patient advocate, this employee of the ethics department reluctantly became the advocate for the patient. Coincidentally, the patient lived in a retirement home and did not have any family. Over a two-week period the patient called this employee many times a day, asking her to get copies of her medical chart, verify documentation in her chart, confirm her treatment plan, and keep her company. The ethics consultant was spending about 10 hours a week with the patient, and this was affecting her other job responsibilities. One question is had the patient been introduced to a patient advocate at the beginning of her stay might it have eased some of her anxiety regarding her medical condition, making her demands on the institution less cumbersome?

Hellwig & associates (2003) report that physicians take on a paternalistic role with their patients which assumes the physician knows what is best for the patient. A new niche market for physicians is a fee-for-service practice. These are sessions where a physician will meet with a patient to help the patient deal with difficult life decisions, such as a newly-diagnosed, life-threatening disease. The doctor may also help patients tell their families, and become a resource for referring patients to specialists for their illnesses. For example, the specifically trained cancer patient advocate physician will

help the patient communicate with his family by assigning him to a psychologist, go over the medications he will be taking, and set up further appointments with other health care professionals. In this role the fee-for-service patient advocate is acting as a communication specialist, bringing together resources for the patient (Bernay, 2001). Another question is couldn't a patient advocate employed by the hospital with specific training to cancer patients fulfill most of the duties entailed by this fee-for-service physician?

Rationale

Tran, Haidet, Street, O'Malley, Martin & Ashton (2002) conclude that open communication between patients and physicians is an integral part of obtaining good healthcare because it enhances the patient's ability to adhere to treatment regimens, recall physician's recommendations, and achieve better health outcomes and patient satisfaction. When there is a lack of communication, patients are not clear on the doctor's recommendations; therefore, they become anxious. The anxiety can cause a breakdown in communication, and physicians become frustrated when patients are not following their instructions regarding their healthcare. As a result, there are patients who are not satisfied with the care they receive. A common complaint on patient satisfaction surveys is that their doctors do not communicate effectively (Tran et al., 2002). This study concludes that simple interventions with patients can help them communicate more effectively with their healthcare providers. The role of the patient advocate is to lessen fear and anxiety in the patient, so the lines of communication can open up between healthcare provider and patient resulting in greater patient satisfaction.

A study investigating the differences between male and female patients found that women are more demanding than men in a hospital setting, and younger women more so than older (Foss, 2002). It questions whether these findings are true because of the traditional female role of mothering, being used to advocating for their children, or the possibility that they have a sense of powerlessness in the hospital, and this is how it is expressed. The author concludes that there is a need for hospital staff to be sensitive to the different needs of male and female patients (Foss, 2002).

Although patient advocacy has gained popularity by serving various groups in numerous communities, no formal studies have been done to show the importance in hospitals. There are many people in a hospital setting who could fulfill different aspects of the patient advocacy role. However, it might be more efficient to have one person the patient can rely on to discuss their concerns regarding their hospital stay. It might help diminish miscommunications between patients and healthcare providers, which could help lessen the fear and anxiety people may experience during a hospital stay resulting in greater patient satisfaction.

Patient advocates may visit with patients as part of their rounds or be summoned by a healthcare provider or administrator in the hospital. The responsibilities of the advocate entail listening to patient complaints as well as compliments about the hospital during their stay. For example in the present study, patient A expressed concern regarding hospital bills to the patient advocate. The patient advocate relays this information to the social worker on the unit to see what can be done to help the patient. Patient B was very impressed with all the staff on the unit, but was concerned about a

fever that kept going up and down. In this situation the patient advocate asked the patient if there was anything he could do to help him and the patient declined commenting, "I am confident the healthcare staff is doing everything they can." By engaging in conversation, the patient advocate works to lessen the fear and anxiety the patient may feel. The advocate will keep in mind the patients' rights such as receiving complete information about their diagnoses, treatments, and prognoses. The goal of the patient advocate is to deter any unfavorable interactions patients may have while in the hospital as well as to gain their trust. Patient advocates can also be described as healthcare comforters because they are there to make sure a patient's stay in the healthcare setting is as comfortable as possible.

Methods

Participants

A convenience sample (N=3) was obtained from the inpatient Hematology/Oncology Unit from a tertiary care center in upstate New York. This medical center has been acknowledged for its research contributions and clinical care excellence especially within the area of Oncology. Patient advocates are currently volunteers that are an integral part of this institution focusing on the patients' needs in a way no other position is able to fulfill because of the increasing demands of the healthcare industry.

The subjects of this study, three Caucasian males with a mean age of 55 resided on the Oncology/Hematology unit for the duration of the study. No subjects in the study had been previously visited by patient advocates. They were at least 18 years of age, and

were able to understand English. All the participants in this study had been diagnosed with cancer within the past six months and had no cognitive or physical limitations preventing them from independently completing a questionnaire. All the subjects were chosen by the primary investigator and signed consent forms.

Patients were approached by the primary investigator who explained the present study and their participation. When the patients agreed to participate they signed the consent forms. The primary investigator then left the room and returned to receive the first of two completed questionnaires. The second questionnaire was completed by the subject approximately one week later, after they had been visited by a patient advocate at least two times.

Design and Procedure

An ABA design was used to test the efficacy of patient advocates on patients at a hospital in Rochester New York.

It was hypothesized that interventions by patient advocates significantly reduce fear and anxiety levels with patients who have been diagnosed with cancer. The Hospital Anxiety and Depression Scale (HADS), the Personal Report of Communication Apprehension (PRCA-24), and the Child Surgery Worries Questionnaire (CSW) measured the dependent variable, the anxiety level of patients.

Measurement Tools

The PRCA-24

The PRCA-24 (see appendix A) measures anxiety in people. Communication apprehension (CA) is individual's level of anxiety they experience when communicating

with another person (McCroskey & Richmond, 1997 and Booth-Butterfield, Chory & Beynon 1997). The reason this scale was chosen for this study was people with CA will experience it in all contexts, so it makes sense for patients to experience this with interpersonal communication with their healthcare providers. Once this measure informs the researcher whether the subjects are generally communicatively apprehensive it can be related to the HAD scale to see if there is a correlation. Although a widely researched variable, there is little literature on the study of communication apprehension in the healthcare field. Anxiety can be caused by the need to present personal information to a stranger who appears to be very busy (Foley & Sharf, 1981). In a sample of adults this scale demonstrated a scale reliability of .96 (Booth-Butterfield & associates, 1997).

The CSW

The CSW Scale (see Appendix B) was included because it addresses concerns not addressed by the HADS scale. For example, the CSW scale asks patients to rate how worried they will be about not recovering from the illness and how the hospital staff will treat them (Quiles, Ortigosa, Mendez, & Pedroche, 2000). This scale measures children's fears and worries in respect to invasive medical procedures. This scale was used because adults and children experience fear while being hospitalized and this measure was an acceptable way to determine if a person experiences fear and anxiety were they worried as well? Is there a direct correlation between fear, anxiety and worry? An exploratory factor analysis identified three factors: worries about hospitalization, medical procedures, and the illness's repercussions. A Cronbach alpha of 0.876 was reported (Quiles, Ortigosa, Mendez, Pedroche, 2000).

The HADS

The HADS (see Appendix C) was created to be used in general medical settings. The questions are split into two subscales: seven questions related to anxiety and seven questions related to depression. The questions related to depression are used to determine if a patient has completely lost enjoyment in his life, also known as anhedonia. The scales are measured on an ordinal scale of 0-3, 0 being the most agreeable and three the least. The HADS is a reliable and valid instrument for assessing anxiety and depression in medical patients (Hermann, 1996) and has been tested for validity with various populations and has a Cronbach alpha of 0.89 (Wing, Cooper, & Sartorius, 1987). It is recommended that for a screening instrument the coefficient alpha should be at least 0.80. This scale is important to use in this study because we are interested in measuring the levels of fear and anxiety in hospitalized cancer patients. It will be interesting to note if a person scores high on the CA test will they also on the HAD scale.

Patients were approached by the primary investigator and asked to participate in a research study looking at the effect of the intervention of a patient advocate on fear and anxiety levels. The primary investigator explained the role of a patient advocate and informed the subjects that they would be visited by a patient advocate regardless of whether they chose to participate in the present study. When the subjects agreed to participate they were asked to sign the consent form and complete the first of two questionnaires. The first questionnaire was the pre-advocate questionnaire and the post-advocate questionnaire would be administered approximately one week later. The

subjects were told they could remove themselves from the study at any time with no consequences.

Upon completion of the consent form, subjects were handed the pre-advocate questionnaire to obtain baseline information regarding fear, anxiety and worry levels. The primary investigator left the room and returned approximately one half hour later to retrieve the questionnaire. During the next five days the subject was visited by a volunteer patient advocate. When the subject had been seen at least twice, the primary investigator returned to administer the second questionnaire (post-advocate questionnaire). The primary investigator left the room. Once completed, the subject was thanked and the primary investigator brought the information to be placed in a locked cabinet.

Results

The questionnaire began with the CSW with a scale of 0-108 and a central value of 51. The pre-test mean was 8.0 and the post-test was 7.3. The PRCA-24 followed with a scoring range of 24-120 and a mean of 65. Pre-patient advocate, the mean was 74 and post-patient advocate mean was 68.0. The final scale was the HADS with the high anxiety responses receiving higher test scores with an optimum cut off threshold of 19. Pre-patient advocate, the mean was 31.3 and the post-patient advocate mean was 27.0. When the anxiety and depression scales were separated, pre-patient advocate the mean was 15.3 and post-patient advocate was 13.0 for depression. For anxiety, the pre-patient advocate mean was 16.0 and post was 14.0. Patient A had one missing item on the

PRCA-24 scale and one on the HADS scale. A mean was substituted for each missing item. (See Table 1).

Table 1

Mean scores before and after meeting with a patient advocate

	Pre-patient advocate	Post-patient advocate
PRCA-24	74	68
HADS	31.3	27
Anxiety	16	14
Depression	15.3	13
CSW	8	7.3

Discussion

The fear and anxiety levels in our sample (N=3) decreased in all three patients. The research supports the idea that patients who are generally communicatively apprehensive also score high on the HAD scale. This is not surprising because when people who are generally communicatively apprehensive enter a situation with the potential for added stress and anxiety it would make sense their stress and anxiety levels may increase. Although the sample size was not large, this study serves as a basis for further research on the effects of patient advocates on hospitalized patients. In addition to the statistics, written reports were completed by the patient advocate which is part of their volunteer job. It is worth noting that one of the subjects expressed concerns regarding having to pay his hospital bill to the patient advocate. The patient advocate wrote up the patient's concern, asking for a social worker to assist the patient. This worry that may have been causing the patient some anxiety was addressed by the patient advocate. There is a misconception that cancer patients would rather have a healthcare provider who is an expert in his field than a person they can confide in (Fallowfield, 1992).

Another subject revealed while talking to the patient advocate that he "was concerned because he literally lived off the land in a very basic dwelling, and didn't know how he was going to take care of himself." A man who has provided for himself his entire life may not be able to any longer and this may cause him to worry or become anxious about going home. He was comfortable enough to say to a patient advocate regarding his situation, "I don't know if I can take care of myself any longer." This

conversation resulted from the patient advocate taking the time to discuss the patient's feelings regarding his health care situation.

One of the subjects received a phone call while speaking to the patient advocate. The patient was informing the caller of his condition and explained to the caller he was going to tell various family members different versions of the truth so they wouldn't be so upset. This person came from a family with six brothers and six sisters. This means that besides being concerned about his own health situation he was burdened with how his family was going to deal with his diagnosis, plus keep the lies straight. This factor may cause the patient fear, anxiety and stress.

A lack of communication between patients and healthcare providers commonly result in the patient feeling anxious, taking longer to recover, and becoming dissatisfied with their care (Newell 1987). The present study found that our subjects were very satisfied with their care. This was apparent from the reports written by the patient advocate. Each subject complimented the staff at the hospital and relayed they were comfortable with their stay. This may be due to the patient advocate's ability to take time and engage in conversation with patients, thereby lessening the anxiety a patient may be feeling, resulting in better communication with their healthcare providers and greater satisfaction with their hospital stay.

Cancer patients are afraid to talk to their doctors about feelings of depression (Williams, 2001). The present study showed pre-patient advocate that the subjects scored higher than average on the HADS items measuring depression. The post-patient questionnaire showed a decrease in depression. The patient advocate was able to establish

interpersonal relations with the subjects which were shown in the patient advocate reports. This relationship may have lessened the fear and anxiety so commonly felt by newly diagnosed cancer patients.

The sample size of the study was a limitation, although it serves as a pilot study for further investigation. The choice of using only one unit in the hospital was partly responsible for the small sample size. The fact that only men were in the study limited the scope of the research. Demographically, the subjects were similar, limiting further comparisons of the finding. There were internal factors that could have been contributing to the results such as the new diagnosis and all the information that is being given to them. Two of the patients shared rooms with other patients which may have added stress. The unit is very busy and the patients may have been worrying about bothering the staff when they needed assistance. All of these variables may have caused the anxiety and stress levels to escalate in the subjects.

Despite the limitations of this study, this study provides a direction for research in a number of areas. First, the study provides tentative support for patient advocates having an effect on fear and anxiety levels of hospitalized cancer patients. Future research could focus on the effect of patient advocates with patients with various illnesses, demographics, and concerns regarding their hospital stay. Second, further research could investigate what effect, if any, the intervention of a patient advocate has on the patient/healthcare provider relationship. This research could be done by doing a qualitative and/or quantitative study with patients and doctors. A combination of questionnaires and interviewing sessions would be beneficial to see how patients and

healthcare providers view their interpersonal communications, what they feel the barriers are with communicating ideas plus what can be done to improve their relationships.

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Appendix A

The Personal Report of Communication Apprehension-Self Report (24)

Below are 24 statements regarding your feelings about communication with other people. Please indicate in the space provided the degree to which each statement applies to you by marking whether you **(1) strongly agree (2) agree (3) are undecided, (4) disagree (5) strongly disagree** with each statement. There is no right or wrong answers. Many of the statements are similar to other statements. Do not be concerned about this. Work quickly; please record your first impression.

- _____ 1. I dislike participating in-group discussions.
- _____ 2. Generally, I am comfortable while participating in-group discussions.
- _____ 3. I am tense and nervous while participating in a group discussion.
- _____ 4. I like to get involved in-group discussions.
- _____ 5. Engaging in a group discussion with new people makes me tense and nervous.
- _____ 6. I am calm and relaxed while participating in-group discussions.
- _____ 7. Generally, I am nervous when I have to participate in a meeting.
- _____ 8. Usually, I am calm and relaxed while participating in meetings.
- _____ 9. I am very calm and relaxed when I am called upon to express an opinion at a meeting.
- _____ 10. I am afraid to express myself at meetings.
- _____ 11. Communicating at meetings usually makes me uncomfortable.
- _____ 12. I am very relaxed when answering questions at meetings.
- _____ 13. While participating in a conversation with a new acquaintance, I feel very nervous.
- _____ 14. I have no fear of speaking up in conversations.
- _____ 15. Ordinarily I am very tense and nervous in conversations.
- _____ 16. Ordinarily I am very calm and relaxed in conversations.
- _____ 17. While conversing with a new acquaintance, I feel very relaxed.
- _____ 18. I am afraid to speak up in conversations.
- _____ 19. I have no fear of giving a speech.
- _____ 20. Certain parts of my body feel very tense and rigid while giving a speech.
- _____ 21. I feel relaxed while giving a speech.
- _____ 22. My thoughts become confused and jumbled when I am giving a speech.
- _____ 23. I face the prospect of giving a speech with confidence.
- _____ 24. While giving a speech, I get so nervous I forget facts I really know.

Appendix B

The Child Surgery Worries Questionnaire

Hospitalizations can be very stressful. Below are a series of situations that people may encounter when admitted into a hospital. We are interested in how you are feeling regarding your hospitalization. Please answer the following questions using the scale provided.

PLEASE CIRCLE THE ANSWER THAT BEST DESCRIBES HOW YOU ARE FEELING

	Not At All Worried	A Little Worried	Moderately Worried	Considerably Worried	Extremely Worried
1. Not Recovering from the illness	0	1	2	3	4
2. Not being able to do the same things as before the illness	0	1	2	3	4
3. Being hurt during a procedure	0	1	2	3	4
4. Not being able to bear pain	0	1	2	3	4
5. Dying	0	1	2	3	4
6. Injections	0	1	2	3	4
7. Having to have a needle in my arm for hours	0	1	2	3	4
8. Health care staff taking blood from my body	0	1	2	3	4
9. Waking up during a procedure	0	1	2	3	4

10. Leaving my loved ones before a procedure	0	1	2	3	4
11. Being naked in from of the health care staff	0	1	2	3	4
12. The food in the hospital	0	1	2	3	4
13. Knowing when I will be able to leave the hospital	0	1	2	3	4

14. Showing fear or pain	0	1	2	3	4
15. The way the health care staff will treat me	0	1	2	3	4
16. My loved ones being afraid	0	1	2	3	4

Appendix C

Hospital Anxiety and Depression Scale (HADS),

Many times people have feeling of depression or anxiety regarding their illness; we would like you to tell us about how you are feeling. In the questions below please **CIRCLE** the answer that best describes how you are feeling today.

1. I feel tense or “wound up.”

- 1. Most of the time**
- 2. A lot of the time**
- 3. From time to time, occasionally**
- 4. Not at all**

2. I still enjoy the things I used to enjoy.

- 1. Most of the time**
- 2. A lot of the time**
- 3. From time to time, occasionally**
- 4. Not at all**

3. I get a sort of frightened feeling as if something awful is about to happen

- 1. Most of the time**
- 2. A lot of the time**
- 3. From time to time, occasionally**
- 4. Not at all**

4. I can laugh and see the funny side of things.

- 1. Most of the time**
- 2. A lot of the time**
- 3. From time to time, occasionally**
- 4. Not at all**

5. Worrying thoughts go through my mind.

- 1. Most of the time**
- 2. A lot of the time**
- 3. From time to time, occasionally**
- 4. Not at all**

6. I feel cheerful.

- 1. Most of the time**
- 2. A lot of the time**
- 3. From time to time, occasionally**
- 4. Not at all**

7. I can sit at ease and feel relaxed.

1. Most of the time
2. A lot of the time
3. From time to time, occasionally
4. Not at all

8. I feel as if I am slowed down.

- 1. Most of the time**
- 2. A lot of the time**
- 3. From time to time, occasionally**
- 4. Not at all**

9. I get a sort of frightened feeling like “butterflies” in the stomach.

1. Most of the time
2. A lot of the time
3. From time to time, occasionally
4. Not at all

10. I have lost interest in my appearance.

- 1. Most of the time**
- 2. A lot of the time**
- 3. From time to time, occasionally**
- 4. Not at all**

11. I feel restless as if I have to be on the move.

- 1. Most of the time**
- 2. A lot of the time**
- 3. From time to time, occasionally**
- 4. Not at all**

12. I look forward with enjoyment to things.

1. Most of the time
2. A lot of the time
3. From time to time, occasionally
4. Not at all

13. I get sudden feelings of panic.

- 1. Most of the time**
- 2. A lot of the time**
- 3. From time to time, occasionally**
- 4. Not at all**

14. I can enjoy a good book or radio or TV program.

1. Most of the time

2. A lot of the time
3. From time to time, occasionally
4. Not at all

Appendix D

Now we would like to know a little about you.

1. Age at your last birthday, _____ years

2. Gender

- ☐ Male
- ☐ Female

3. Race

- ☐ African American
- ☐ Caucasian/Non-Hispanic
- ☐ Hispanic
- ☐ Asian
- ☐ Other: _____

4. Do you live alone?

- ☐ Yes
- ☐ No

If no, with whom do you live? _____

Thank you for your participation.

Appendix E

Informed Consent to Participate in Research

Principal Investigator: Joan C. Vezelis
Telephone No.: 275-7750

University of Rochester Medical Center
Strong Memorial Hospital

Title of project: A study of fear and anxiety in patients diagnosed with cancer during their hospital stay.

You are being asked to volunteer as a participant in a research study. This form is designed to provide you with information about this study.

Purpose: Patient advocates are volunteers and staff members who visit with patients throughout their hospital stay to talk with them about how they feel about their stay at Strong Memorial Hospital. The purpose of this study is to see if the visits a patient advocate makes to the patients has an effect on the level of fear and anxiety a patient may be feeling. Newly diagnosed cancer patients frequently have fear and anxiety when being hospitalized. These feelings may have an effect on how the patient and healthcare providers communicate. It is our goal to have each patient comfortable and at ease while in our hospital.

The approximate length of your participation will be two weeks.

Procedure: A patient advocate who is part of the Patient Advocacy Program here at Strong Memorial Hospital will visit you. Most of the patients hospitalized here receive visits by patient advocates. You will fill out a questionnaire today (before you have been visited by a patient advocate) and again in approximately one week. Each questionnaire will take you approximately ten minutes to fill out. The survey will ask you how you feel about being hospitalized.

Benefit: The benefit of this study is to show the positive effects the visit of a patient advocate has on how patient does feel about their stay at Strong Memorial Hospital.

Risk: The risk to the patient is the survey could increase levels of fear and anxiety. If you feel extremely fearful or anxious regarding this study please let me know or your nurse and you will be removed from the study.

Confidentiality: Your room number and the number assigned for this study will be on a master list. This is how you will be identified for this study. This information will be kept confidential in a locked drawer. No record of your name or any other information that could identify you will be documented.

Subject Rights: Any questions you have regarding this research can be answered by Joan C. Vezelis at 275-7750. Your participation in this study is voluntary and you are free to withdraw at any time. You will be given a copy of this form to keep.

Thank you for considering participating in this research study.

Signature of Participant

Date

Signature of Witness

Date

Signature of person who obtains consent

Date

Table 1

Mean scores before and after meeting with a patient advocate

	Pre-patient advocate	Post-patient advocate
PRCA-24	74	68
HADS	31.3	27
Anxiety	16	14
Depression	15.3	13
CSW	8	7.3