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An Analysis of the Services Offered to Cancer Patients in the State of Maine

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AN ANALYSIS OF THE SERVICES OFFERED TO CANCER PATIENTS IN THE STATE
OF MAINE

by

Joseph Claar

A Thesis Submitted in Partial Fulfillment
of the Requirements for a Degree with Honors
(Nursing)

The Honors College

University of Maine

May 2016

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Abstract

People who are diagnosed with cancer should have access to information about their disease. These patients require the proper supportive care to meet their needs, and in order to do that; many people are turning to cancer support centers. These centers offer complementary and alternative medicine (CAM) such as yoga, meditation, reiki, support groups, etc. Cancer support centers have been developed that try to reach as many people as possible with their services. Maine is a very rural state so not everyone has easy access to complementary and alternative medicine practices, but these cancer support services can be found at various facilities throughout the state. Cancer support centers do everything that they can to make sure that patients and families affected by cancer receive high-quality information and support. In order to make sure that these centers are responsive to the needs of the people affected by the disease, I have conducted a study to determine what services the patients have found to be beneficial.

One hundred and twenty two participants took the survey. Survey participants found a majority of the services listed to be beneficial to their health. Exercise/fitness group was the most beneficial and hypnosis was the least beneficial. Common themes came up in the survey that included topics such as the need for more support centers and less traveling for members.

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Review of Literature

There have been breakthroughs in cancer treatments and technologies over the years, so cancer patients are living longer lives and surviving the disease. Now there is a growing population of people affected by cancer because of the survivors and prevalence of cancer. Schneerson, Taskila, Gale, Greenfield, and Chen (2013) stated that survivors of cancer are more likely to suffer from health problems that are secondary to the cancer such as nausea, anxiety, fatigue, depression, and pain. Patients have reported feeling isolated and abandoned after ending treatment. This would impact their quality of life and may further their depression and anxiety. Cancer patients can use different resources in order to improve their quality of life and long-term health outcomes.

Complementary and alternative medicine (CAM) can be defined as: “a variety of different medical systems and therapies based on the knowledge, skills, and practices derived from theories, philosophies and experiences used to maintain and improve health, as well as to prevent, diagnose, relieve, or treat physical and mental illnesses” (Schneerson et al., 2013, p. 418). This concept encompasses several different types of therapies such as acupuncture, meditation, reflexology, massages, etc. Complementary and alternative medicines are not always used in conventional healthcare systems but cancer patients have utilized CAM for years. It’s a way for them to regain control of their bodies and develop therapeutic relationships with healthcare professionals and care providers. Complementary and alternative medicine has also been linked to alleviating side effects from treatment and improving quality of life (Schneerson et al., 2013). Cancer patients use these services more than the healthy population, because they have a strong belief in these therapies and are hopeful about the outcomes.

A study by Ben-Arye et al. (2012) explained the association of complementary and alternative medicine along with spirituality in oncology programs. The researchers explored the patients' perspectives on these topics in order to see if the patients' needs were being addressed. A questionnaire was distributed to a group of patients attending a community-based oncology service in Israel. Their results found that most of the patients were currently undergoing cancer treatment while the others participating were in follow-up surveillance of their cancer. Participating in complementary and alternative medicine services was associated with having a younger age and being of Jewish religion.

An important aspect of this study found that patients who have a higher level of spiritual quest are more likely to participate in complementary and alternative medicine practices (Ben-Arye et al., 2012). Patients who deemed themselves more spiritual than the other participants also expressed more expectations from the services that they were using. Themes such as lessening chemotherapy side-effects, improving daily functioning, and coping with the disease were expected from the complementary and alternative medicine counseling that they were receiving. This group also wanted spiritual and emotional support for the patient and their family. This study also found that participants with a higher level of spirituality expected their social worker to be more involved in building their complementary and alternative medicine treatment plan (Ben-Arye et al., 2012).

Brauer, El Sehamy, Metz, and Mao (2010) reported that cancer patients and their family members are turning to the Internet to educate themselves about their disease and treatment, including complementary and alternative medicine. Not much was known about how national leading cancer centers represented these therapies through their

websites until now. The researchers decided to simulate a perspective information-seeking patient or family member and they browsed through several websites. The National Cancer Institute has designated comprehensive cancer centers and the researchers examined 41 of their websites for this study (Brauer et al., 2010). There were only two researchers who evaluated the websites, but their ratings were adequately correlated between them. These researchers looked at all of the complementary and alternative medicine information on these websites by using a scale. This particular scale had 4 items that could be rated, which included overall, information, presentation, and navigation.

Their results showed that 29% of these centers did not have functional websites regarding information related to complementary and alternative medicine (Brauer et al., 2010). There were common types of complementary and alternative medicine activities, which included meditation, nutrition, spiritual support, and yoga. Massage and music therapy were also listed. Roughly 56% of the websites presented information on support groups for patients. Only 7 of the 41 websites received a composite score that was excellent, which shows the need to redesign websites in order to make them more suitable to provide information (Brauer et al., 2010). There should be more development of these websites in order to provide patients with the correct information so they can be empowered and get the treatment they need.

Manning and Dickens (2007) distributed surveys to cancer patients who attended cancer support groups. These people were asked to choose from four possible responses for each question. The answer options ranged from not important to very important. The clients who participated in the study were also provided an area where they could

describe their own experience for each question. People who responded to the survey wanted support centers to provide a “holistic approach to their condition and provide services that fixed the whole person and not just the disease” (Manning & Dickens, 2007, p. 34). One of the respondents stated: “I have to keep hoping the drugs I am taking are fixing one set of problems but it’s the other problems cancer brings you are left struggling with” (Manning & Dickens, 2007; p. 34). Patients wanted a place that was a “white coat free zone” where they could relax and recharge their batteries. These people also wanted help understanding their diagnosis and they wanted to learn about the different treatment options. In terms of emotional support and counseling, patients wanted to talk to someone who would listen and understand what they were going through such as an ex-patient (Manning & Dickens, 2007). Former patients would know more about what current patients are going through and would not be too professional like a counselor might be.

Of the patients that Manning and Dickens surveyed, 82% thought that it was important for these support centers to provide programs that could help these patients talk to their family and friends about cancer (Manning & Dickens, 2007). There were many participants who wanted information regarding sexuality and relationships. Respondents also wanted support centers to provide access to complementary therapies. Older people actually did not find complementary therapies to be as important. Survey respondents also wanted demonstrations on how to feel and look good when battling cancer. People who are affected by cancer have a wide variety of needs. These needs can depend on the person’s age, gender, type of cancer, and how far along they are on their journey (Manning & Dickens, 2007). This study clearly showed that patients want access to

information about various topics related to cancer and support services to maintain a good quality of life.

Frenkel and Cohen (2014) stated that cancer patients are requesting more information about complementary and integrative medicine. Patients and family members are turning to healthcare professionals for informed advice and need proper communication. Healthcare professionals need to be ready to assist these patients having intense emotions while discussing the usage of complementary and integrative medicine. Patients who are affected by cancer may feel as though they are experiencing an existential life crisis. Therefore, effective communication between the healthcare provider and the patient is crucial (Frenkel & Cohen, 2014). Healthcare professionals will have to establish trust with patients and family members. This study identified communication as being a core clinical skill in medicine, especially cancer care.

In order to deliver high quality care, patients need to be satisfied with the level of communication that is being delivered to them. Communication affects patients' decision-making, well being, and compliance. Healthcare professionals should be sensitive to the patient when discussing complementary and integrative medicine. The study concluded that effective communication requires physicians and nurses to listen, encourage hope, and convey empathy. The process of communicating can be divided into two parts called the "how" and the "what" (Frenkel & Cohen, 2014). The "how" involves the attitude of the healthcare professional, the gathering of pertinent information, and addressing the patients' needs. The "what" relates to the process of exchanging information and assisting patients with decision-making regarding complementary and

integrative medicine. Overall, when working with cancer patients and their families, healthcare professionals will need to be compassionate and provide reliable information.

Lydon, Ryan-Woolley, and Amir (2009) examined cancer patients' access to self-help group services. These services provide guidance for these patients in order to help them deal with their emotional and everyday needs. A telephone survey was used to collect data on the structure and function of support groups for cancer patients. The leaders of cancer support groups in England were called in order to get their perceptions of the features and functions of the supports groups. Thirty-seven groups were surveyed for this study and the researchers found that 23 of these groups were peer-led, while a nurse or other healthcare professional ran the other groups (Lydon et al., 2009). The results from their surveys concluded that these groups served the purposes of providing emotional support, information/advice, as well as social opportunities for its members. One of the challenges identified from these surveys was the need to raise awareness about groups in order to attract members. Nurses have the chance to promote these support groups and encourage people to attend.

Zabalegui, Sanchez, Sanchez, and Juando (2005) discussed how nurses are always trying to give patients with cancer more emotional support and strengthen their adaptation to the disease. Psychological interventions such as support groups have improved adaptation for patients with cancer by reinforcing effective coping mechanisms (Zabalegui et al., 2005). The researchers looked at the effectiveness of support groups by reviewing the evidence behind them. A meta-analysis was performed on randomized controlled trials that evaluated support groups for cancer patients (Zabalegui et al., 2005). The researchers selected twenty studies that involved randomized clinical trial designs.

The results of the study indicated that participating in support groups improved patients' emotional states such as depression and anxiety. A significant association was also found between support groups and illness adaptation, quality of life, and marital relationships. The study concluded that support group participation for cancer patients had a positive impact in these specific areas and that nurses should be promoting participation in support groups (Zabalegui et al., 2005).

Overall, the review of literature shows cancer patients wanting to use complementary and alternative medicine. Cancer patients and their families are trying to find more information on CAM services by using various outlets. They're turning to the Internet and healthcare providers in order to educate themselves on the topic. CAM services have the potential to help patients and their families and numerous ways.

Methods

Purpose

The purpose of this study was to identify complementary/alternative therapies and support services that cancer patients, cancer survivors, and their caregivers found beneficial to their health. This study investigated the use of these complementary/alternative medicine (CAM) practices such as yoga, pilates, reiki, support groups etc. through the perception of the patients themselves. This knowledge will assist cancer support organizations in enhancing their services for cancer patients in the future. There are several cancer support centers in Maine that provide free services to cancer patients, cancer survivors, and their caregivers. The Patrick Dempsey Center for Cancer Hope & Healing in Lewiston and the Beth C. Wright Cancer Resource Center in Ellsworth were selected to participate in this study. These centers offer alternative types of healing such as yoga, pilates, reiki, support groups etc. These programs assist patients with cancer by helping them maintain their optimum health. The survey was distributed through email to the current and past users of these two cancer support centers. This study identified what these clients found beneficial.

This research is a descriptive study because information was collected without changing the environment, nothing was manipulated, and the research was not experimental. A descriptive study was used for this research because human participants were surveyed in order to provide information on cancer resource centers.

Participant Eligibility

Participants were recruited from the Patrick Dempsey Center for Cancer Hope & Healing in Lewiston and the Beth C. Wright Cancer Resource Center in Ellsworth. The

Cancer Community Center in Portland was on board with this study as well but they ended up not being able to send out the survey. The survey was distributed through email to the current and past users of the centers, which included patients and their caregivers. Surveys were emailed through a contact person at each center. Eligible participants needed to have a valid email address, which was used to send the survey to the patients. The type and stage of the cancer did not matter. There was no discrimination of participants based on gender, age, or ethnicity. Participants had to be at least 18 years of age.

Study Tool

The tool used in this study was a survey created by the principal investigator, Joseph Claar. The survey has not been validated but was reviewed by the Internal Review Board and by the support centers. Edits were made to the first draft of the survey and parts of the survey were changed based on their comments and suggestions. The final tool consisted of 18 items that pertained to the participant's perceptions of support center services they thought were beneficial to their health. The participants were asked to mark the circle that most closely corresponded to how beneficial the complementary therapies/cancer support services were to their health. The choices were "Yes", "No", and "Not applicable/Did not use". Then there were 9 demographic questions for the patient to answer through multiple choice and short answer. There was also one open-ended question that asked for participant feedback about the survey. This tool can be found in Appendix C.

Institutional Review Board

A proposal was submitted to the IRB at the University of Maine, Orono. The study received final approval to begin. The study was sent out to the cancer support centers and they wanted some changes to be made before they agreed to send it out. The Chair of the IRB approved revisions that were made through an addendum to the proposal.

Since the Patrick Dempsey Center for Cancer Hope & Healing is a part of Central Maine Medical Center, the institution required an IRB approval through them as well. Lois Jones, the IRB Administrator & Risk Compliance Coordinator, required an Inter-Agency Agreement for the University of Maine, Orono that the Institutional Officer had to sign. IRB approval was not necessary for the Beth C. Wright Cancer Resource Center.

Confidentiality

This study used an electronic survey in order maintain confidentiality. The survey was distributed through the cancer support centers by using the participants' email addresses. The email that was sent to them included a link to the survey using Qualtrics, an online survey program used by the University of Maine. This allowed for anonymous collection of responses. Participants had an informed consent that they had to read and agree to in order to move forward to the survey (Appendix B). Since the survey was electronic, the participant had multiple-choice options of either "Agree" or "Disagree". Informed consent of participants was obtained by participants answering "Agree". If a participant chose "Disagree" then they would be prevented from taking the survey and sent to a different page that read: "You are not allowed to progress forward to the survey because you did not agree to the Informed Consent. Thank you for your time." There was

no compensation offered for participants, and informed consent included the completely voluntary aspect of this study.

Survey Distribution

Surveys were distributed through the cancer support centers. The principal investigator went through a contact person at the Patrick Dempsey Center for Cancer Hope & Healing in Lewiston and the Beth C. Wright Cancer Resource Center in Ellsworth. The Executive Director at the Patrick Dempsey Center for Cancer Hope & Healing and the Executive Director at the Beth C. Wright Cancer Resource Center were told about the study and approved the distribution of the survey through their mailing list.

The contacts at these centers were sent a first email that explained that their next step would be to distribute the upcoming email (Appendix D). The contacts at these support centers were asked to distribute the cover letter email to members that they had in their mailing list. Then a follow-up email was sent shortly after that which included a cover letter for the study. Each email and cover letter was specific to each institution. The cover letter explained what the survey was for and included a Qualtrics survey link (Appendix A). If they chose to click on the link, the participants were taken to the informed consent of the survey.

Results

Participants:

Participants were surveyed through 2 out of the 3 cancer support centers. Seventy-two people from the Patrick Dempsey Center for Cancer Hope & Healing in Lewiston, 21 people from the Beth C. Wright Cancer Resource Center in Ellsworth, and 3 from the Cancer Community Center in Portland.

Of the participants who took the survey, 73% of them had been diagnosed with cancer and 27% were support people for the cancer patients. Of the survey participants who were cancer patients, 27% started using the cancer support center as soon as they were diagnosed. Thirty-nine percent of survey participants started using the cancer support center during treatment and 34% after treatment. Eighty-nine percent of the survey participants were female while 11% were male. There was a wide range of cancer types including but not limited to breast, prostate, lymphoma, colon, thyroid, lung, ovarian, and melanoma. The average age of the survey participant was 55.6 years old.

A fill in the blank question was included in the survey, which wanted to know about other services the participants had found beneficial to their health. Some of these other support services included essential oils, nutrition education, rehabilitation/physical therapy, healing touch, gardening, cooking, financial guidance, and spiritual/religious programs. People said they liked just having a place to stop and relax. Being around other people facing the same problems and the support from others was found to be beneficial for some people. One participant stated: “Just being around people where I didn't have to explain myself, and was accepted as I am/was.” A few people mentioned that they thought the support for children and teens was useful. One participant claimed: “The

children services were extremely helpful for my children” A couple of survey participants were overwhelmed with the distance to their support center. Some of them felt like they had to travel too far for services. A survey participant mentioned that they didn’t know of any support services in the area that they lived. One person said that the gas cards that were offered to them were helpful. A few other services that people wrote as being beneficial to their health included hospice home care, adventure club, local gym membership, access to a library, and a buddy program. People also wanted help with cosmetics like the use of skin care products, applying makeup, head dressing with hats/scarves, and wig replacements.

Survey participants were asked how long they had been going or had gone to the cancer support center. Answers varied from only a few months to several years. Some people stated that they had been going on and off for a couple years and other made it clear that they only went on occasion. A few participants had just started using support center services.

| CAM Type | # of Yes | Percent of yes | Response total |
|------------------------|----------|----------------|----------------|
| Fitness/Exercise group | 71 | 100% | 71 |
| Massage | 87 | 99% | 88 |
| Educational events | 84 | 97% | 87 |
| Yoga | 69 | 96% | 72 |
| Meditation | 78 | 95% | 82 |
| Support groups | 75 | 90% | 83 |
| Spa Services | 49 | 87.5% | 56 |
| Reiki | 56 | 84% | 67 |
| Cards & Games | 59 | 84% | 70 |
| Art class | 56 | 84% | 67 |
| Reflexology | 37 | 82% | 45 |
| Tai chi | 37 | 80% | 46 |
| Pilates | 31 | 79% | 39 |
| Sewing | 40 | 78% | 51 |
| Knitting | 41 | 75% | 55 |
| Quilting | 34 | 74% | 46 |
| Acupuncture | 34 | 71% | 48 |
| Hypnosis | 14 | 42% | 33 |

Discussion

Most of the patients that took the survey came from the Patrick Dempsey Center, followed by the Beth C. Wright Cancer Resource Center and the Cancer Community Center. About $\frac{3}{4}$ of the survey participants were cancer patients while about $\frac{1}{4}$ were support people for cancer patients. A few participants did state that they were both a patient and a support person. A large majority of the survey participants were female, which does not accurately represent the cancer patient population. Many different types of cancer were listed in the “fill in the blank” section of the survey. There were several participants who said that they had breast cancer. Some people wrote that they had one type of cancer that ended up spreading to another part of their body. Some of them also made it very clear that they were cancer survivors by stating that they had it in the past. Most patients started using the cancer support center during or after treatment rather than right when they were diagnosed with cancer.

The survey was sent to 1,800 people through the Patrick Dempsey Center for Cancer Hope & Healing and 360 people through the Beth C. Wright Cancer Resource Center for a total of 2,160 people. The response rate for this survey was about 6%. One hundred and twenty two people completed the survey. Some people chose not to fill out all of the demographic information so this data is not a complete representation of all the survey participants. It is unknown why there are 3 people from the Cancer Community Center in Portland because they didn't end up sending out the survey. A potential cause of this would be that the cancer patient is a member at both facilities.

The results of this study showed a wide variety of services that were found beneficial by the cancer patients and their support persons. Results were calculated based

on the people who actually participated in the program so that the numbers would not be affected by people answering not applicable. Every person that participated in fitness/exercise group found it to be beneficial to their health. Another complementary and alternative medicine service that was found to be beneficial was massage. Ninety-seven percent of people thought that educational events were benefitted to their health. A large majority of people also found yoga and meditation to be beneficial.

The only complementary service that most people did not find beneficial to their health was hypnosis. Only 33 people participated in this service but 19 of them said that it was not beneficial to their health.

Some of the participants' comments showed support for complementary and alternative medicine. One survey participant stated: "Many patients don't want to define their lives around cancer so survivors prefer to use modalities outside support groups." Other benefits of supportive care are presented through statements like: "A cancer diagnosis involves more than just the patient and all participants require multiple support systems hope this study shows that." The social aspect to CAM was particularly appealing to one individual: "I believe socializing and being part of something not cancer related, but with others who share that experience as well is beneficial to my mental and emotional health."

One survey participant went into detail about the importance of CAM: "Keeping the supportive programs more about loving kindness and permission to be present with oneself and other participants without talking directly about a persons medical condition allows a cancer patient some much needed contact and safety and distance from the disease itself. A person has a disease, but is not a disease that distinction and moments

when a person can make that distinction during treatment are refuges for gearing up for the next dose of chemotherapy, surgery and what have you.”

A few participants were very thankful for their specific support center and were glad to be using their services. One participant wrote: “The Beth Wright center is a wonderful support system for people that need help and counseling. I have benefited so much from the Reiki and help with gas cards.” Another person wrote: “The Dempsey Center played a very large role in my healing as well as that of my family. We couldn't have done it without them!”

Some of the comments reflected the need for various CAM resources in Maine: “wish more support was given in this area would have been helpful to me and I know others”. One person agreed that a study like this one was a necessary research topic for the area: “I think it is important to complete this because it will help the Center decide what services are most beneficial to their participants.” Through the fill in the blank responses, participants said that they do not go to the support center anymore due to its location. This implies that there needs to be more support centers throughout the state of Maine in order to accommodate more cancer patients and their families. If the resources for these new locations are not possible then I think that there should be more funding for people to use gas cards in order to receive services.

Some of the possible limitations to this study would be the fact that it was online. This study required participants to have access to a computer, use the internet, and have a valid email address. This left out people who did not have some of these. Another limitation might be that patients who use support centers have

more interest in CAM than people who don't use the services. Participants also needed to be able to read and understand English.

Conclusion

There needs to be more research done on the use of cancer resource centers. The views of the people who use these centers are very important. Survey participants want access to these services. Some people live in places that are too far away to use these cancer resource centers. There needs to be more of these centers throughout the state of Maine in order to accommodate those who could otherwise benefit from these complementary/alternative medicine services. Listening to cancer patients about what they think is important to their health will allow this field of healthcare to grow. If the majority of people think that a certain service is not beneficial to their health then it's worth looking into whether or not it should be cut. Too often, research looks at how effective a treatment is without consulting the patient. Quality patient-centered care involves meeting the needs of the patient. Cancer patients deserve access to resource centers that can support them in any way possible. The field of complementary and alternative medicine is very unique and is something that should be looked into by future nurses. The cancer support services that were found to be the most beneficial in this survey are topics that nurses could talk to their patients about. Future research in this area will assist nurses in providing more effective care and making suggestions about the use of cancer resource centers.

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Appendix A

Survey Cover Letters

Dear participants:

This has been forwarded to you by The Patrick Dempsey Center for Cancer Hope & Healing. You are invited to participate in a research study titled “An analysis of the complementary services offered to cancer patients in the state of Maine”. I, Joseph Claar, am currently a senior nursing student at the University of Maine in Orono and this research study is the focus of my Honors Thesis. My faculty advisor is Mary Shea, Ph.D., Assistant Professor of Nursing.

In this study, you will be asked to complete an electronic survey. Your participation in this study is voluntary and you are free to withdraw participation at any point. The survey does not collect any identifying information from respondents. All of the responses collected through the survey will be recorded anonymously. I was not given any names or emails for this research study.

Participants must be at least 18 years of age.

Your participation in this study will provide insight into the different types of complementary therapies/cancer support services for cancer patients. Some examples of these include yoga, support groups, knitting, massage, acupuncture, exercise, etc. This knowledge may assist future researchers and cancer support centers in determining what types of complementary therapies/cancer support services are viewed to be useful by the patients, what programs can be enhanced, or what therapies should be implemented. The goal is to find out what cancer patients and caregivers need in terms of non-medical support.

By clicking on the link below you may learn more about the study and begin your participation in this survey. This link will allow you access to an online survey tool called Qualtrics © where the research study survey may be completed.

[INSERT SURVEY LINK HERE]

If you have any questions regarding the survey please do not hesitate to contact myself or Mary Shea, the faculty sponsor. All contact information is provided below.

Thank you for your time. Your participation is appreciated and we thank you in advance for your contribution.

Sincerely,

Joe Claar

207.570.0645

joseph.claar@umit.maine.edu

Mary Shea, Ph.D.

5724 Dunn Hall, Room 216 Orono Maine 04469

207.581.2611

mary.shea@umit.maine.edu

Dear participants:

This has been forwarded to you by The Beth C. Wright Cancer Resource Center. You are invited to participate in a research study titled “An analysis of the complementary services offered to cancer patients in the state of Maine”. I, Joseph Claar, am currently a senior nursing student at the University of Maine in Orono and this research study is the focus of my Honors Thesis. My faculty advisor is Mary Shea, Ph.D., Assistant Professor of Nursing.

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In this study, you will be asked to complete an electronic survey. Your participation in this study is voluntary and you are free to withdraw participation at any point. The survey does not collect any identifying information from respondents. All of the responses collected through the survey will be recorded anonymously. I was not given any names or emails for this research study. Participants must be at least 18 years of age.

Your participation in this study will provide insight into the different types of complementary therapies/cancer support services for cancer patients. Some examples of these include yoga, support groups, knitting, massage, acupuncture, exercise, etc. This knowledge may assist future researchers and cancer support centers in determining what types of complementary therapies/cancer support services are viewed to be useful by the patients, what programs can be enhanced, or what therapies should be implemented. The goal is to find out what cancer patients and caregivers need in terms of non-medical support.

By clicking on the link below you may learn more about the study and begin your participation in this survey. This link will allow you access to an online survey tool called Qualtrics © where the research study survey may be completed.

[INSERT SURVEY LINK HERE]

If you have any questions regarding the survey please do not hesitate to contact myself or Mary Shea, the faculty sponsor. All contact information is provided below.

Thank you for your time. Your participation is appreciated and we thank you in advance for your contribution.

Sincerely,

Joe Claar

207.570.0645

joseph.claar@umit.maine.edu

Mary Shea, Ph.D.

5724 Dunn Hall, Room 216 Orono Maine 04469

207.581.2611

mary.shea@umit.maine.edu

Appendix B

Informed Consent

You are invited to participate in a research study being conducted by Joseph Claar, a senior nursing student at the University of Maine in Orono. My faculty advisor is Mary Shea, Ph.D., Assistant Professor of Nursing. The purpose of this study is to look at complementary services that cancer patients and cancer survivors find beneficial in their day-to-day lives. This knowledge will assist organizations with enhancing their support services for cancer patients. Participants must be at least 18 years of age.

What Will You Be Asked to Do?

If you choose to participate, you will be asked to take an anonymous survey that may take about 10-15 minutes to complete.

Risks

Except for time, there are no risks to you as a participant of this study.

Benefits

This study does not have any direct benefits for you. However, this research will help gain a better insight into determining what types of complementary services patients find beneficial, what programs can be enhanced, or what services should be implemented. These results may be helpful to cancer patients and cancer survivors.

Confidentiality

The survey is anonymous; please do not add your name on the survey. All data is encrypted through Qualtrics © and stored in their firewall protected servers. The only persons with access to data will be the principal investigator of this research,

who will be the sole holder of the username and password. This data will be saved for two years and will be permanently deleted from Qualtrics at that time. The data from the Qualtrics survey will be downloaded to the principal investigator's computer for analysis. This data will be deleted off the computer after two years.

Voluntary

Your participation is voluntary. You may stop at any time or skip any questions you do not wish to answer.

Contact Information

If you have any questions about this study please contact me, **Joseph Claar**, at 207.570.0645 or email: joseph.claar@umit.maine.edu

or

Mary Shea, Ph.D at 207.581.2611 or email: mary.shea@umit.maine.edu

If you have any questions about your rights as a research participant, please contact Gayle Jones, Assistant to the University of Maine's Protection of Human Subjects Review Board at 581-1498 or email gayle.jones@umit.maine.edu.

By clicking "agree" below, you are indicating that you have read and understood the above information and are choosing to voluntarily participate in this research study.

- Agree
- Disagree

Appendix C

Survey

The following items pertain to **your perceptions of what you think is beneficial to your health**. Please mark the circle that most closely corresponds to how beneficial these complementary therapies/cancer support services are to your health.

Yes = Beneficial

No = Not beneficial

N/A = Not applicable/Did not use

| | |
|---------------------------|------------|
| 1. Yoga | Yes No N/A |
| 2. Pilates | Yes No N/A |
| 3. Fitness/Exercise group | Yes No N/A |
| 4. Reiki | Yes No N/A |
| 5. Acupuncture | Yes No N/A |
| 6. Tai chi | Yes No N/A |
| 7. Meditation | Yes No N/A |

| | |
|------------------------|------------|
| | |
| 8. Reflexology | Yes No N/A |
| 9. Massage | Yes No N/A |
| 10. Spa Services | Yes No N/A |
| 11. Hypnosis | Yes No N/A |
| 12. Cards & Games | Yes No N/A |
| 13. Art class | Yes No N/A |
| 14. Knitting | Yes No N/A |
| 15. Quilting | Yes No N/A |
| 16. Sewing | Yes No N/A |
| 17. Support groups | Yes No N/A |
| 18. Educational events | Yes No N/A |

Please tell a little about yourself by filling in the appropriate boxes below.

19. Other services you have found beneficial: _____

20. What center have you been attending for cancer support?

- Cancer Community Center in Portland
- Patrick Dempsey Center for Cancer Hope & Healing in Lewiston
- Beth C. Wright Cancer Resource Center in Ellsworth

21. How long have you been going or did you go to the cancer support center?

_____ Months (Fill in the blank)

22. Have you ever been diagnosed with cancer?

- Yes (If they choose yes, it will take them to questions 23, 24, 25)
- No, I'm a support person for the cancer patient (If they choose no, it will

skip the other questions about cancer and take them directly to question 26)

23. What year were you diagnosed with cancer?

_____ (Fill in the blank)

24. When did you start using the cancer support center?

- As soon as I was diagnosed
- During treatment
- After treatment

25. What type of cancer do you have?

_____ (Fill in the blank)

26. Gender: M or F

27. Age: _____

28. Do you have any comments about this study?

Appendix D

Contact Person Emails

Dear _____,

You are receiving this email because you have agreed to help me, Joseph Claar, with my Honors Thesis research at the University of Maine regarding complementary services to cancer patients in the state of Maine. I will be sending you an email that should be forwarded to the people who have participated in your services at The Patrick Dempsey Center for Cancer Hope & Healing. Thank you for agreeing to be a part of this study. Please let me know if you have any questions.

Dear _____,

You are receiving this email because you have agreed to help me, Joseph Claar, with my Honors Thesis research at the University of Maine regarding complementary services to cancer patients in the state of Maine. I will be sending you an email that should be forwarded to the people who have participated in your services at The Beth C. Wright Cancer Resource Center. Thank you for agreeing to be a part of this study. Please let me know if you have any questions.

Dear _____,

You are receiving this email because you have agreed to help me, Joseph Claar, with my Honors Thesis research at the University of Maine regarding complementary services to cancer patients in the state of Maine. I will be sending you an email that should be forwarded to the people who have participated in your

services at The Cancer Community Center. Thank you for agreeing to be a part of this study. Please let me know if you have any questions.

Author's Bio

Joseph Claar grew up in Orono, Maine and graduated from Orono High School in the top 10 of his graduating class. He started his freshman year undecided and struggled with his career choice. He eventually decided to apply to the nursing program and arrived at this conclusion by being a part of the explorations program, talking to people at the career center, and doing some research on his own. He job shadowed a physician assistant at Eastern Maine Medical Center, which validated his interests in entering a medical profession. He's always enjoyed helping others and believes very strongly in service. He's been involved in the groups Operation H.E.A.R.T.S. and the Orono Student Nurses Association. He believes that nursing is a very rewarding profession and he is excited to make a positive contribution to the profession. He intends to pursue a career in pediatric nursing and eventually join the Peace Corps. He wants this research to be used for the benefit of cancer patients in the state of Maine. He hopes to pursue this field of research in the future through a Master's program.