Coping with Cancer: An Analysis of Social Support Services for Oncology Patients in Kansas City

John Hunninghake
Clendening Fellowship
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Coping with Cancer: An Analysis of Social Support Services for Oncology Patients in Kansas City

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INTRODUCTION/PURPOSE OF THE RESEARCH

Cancer is a chronic illness that requires comprehensive treatment and care that go beyond the medical world’s “standard-of-care.” Meeting the psychosocial needs in cancer care is generally recognized as an important component in the overall quality-of-life of patients undergoing cancer treatment (Greer from Matthews, et al., 2004). Reducing the burden of suffering from cancer is therefore important to a patient’s quality-of-life during treatment. Social support services are available in communities in order to assist cancer patients with psychosocial issues that many cancer patients face after their initial diagnosis. The goal of this project is to research the use of social support services by individuals who are currently undergoing treatment for cancer in the Kansas City area. The study is a non-interventional, epidemiological analysis that asks patients voluntarily to fill out a written survey or respond orally to questions about the type of support services that they use. This project aims to gather statistics about the type and frequency of services that patients use, and then correlate that information with the patient’s opinion about the benefits and short-comings of the services. The resulting information can be used by healthcare providers and nonprofit agencies to respond more effectively to the needs of cancer patients by determining possible reasons that some social support services are used more often than others.

BACKGROUND

Cancer is a potentially fatal illness that is often characterized by a stigma; therefore, cancer patients require additional social support to successfully complete the treatment process. Social support services are defined as “those programs or services offered by a medical clinic or a nonprofit agency that assist patients and their families in handling the myriad physical, emotional, social, and practical problems that follow a cancer diagnosis and its subsequent treatment” (Murphy from Matthews, et al., 2004). These free-of-charge services are usually offered by local and national nonprofit agencies in order to assist cancer patients with various aspects of the cancer treatment process. A full list of social support services and various nonprofit agencies is contained in this project’s survey. Examples of these support services include: support groups, peer-to-peer counseling, transportation, group workshops, educational information about cancer, etc. However, many different ideas existed about what constitutes a “social support service”; therefore, this project will identify the programs and services in the Kansas City area that cancer patients consider as “supportive” for them during their cancer treatment.

Considerable evidence suggests that social networks and support are important contributors to decreased distress and improved psychosocial adjustment among patients at all stages of the disease trajectory (Kornblith 2001). A study by Alex Matthews, et al., entitled “Oncology professionals and patient requests for cancer support services” provided detailed information about patient inquiries to healthcare providers for certain social support services. According to Matthews, cancer education and counseling were the two forms of services that were requested the most. The article indicates that “future studies are needed to determine if patients’ requests are actually fulfilled” (736:2004). Other studies indicate that social support services can be perceived as beneficial or detrimental by the patient, depending on the individual person. According to Helgeson and Cohen, discussion groups have as much potential to adversely affect patients’ illness reactions as they do to positively influence these reactions, due to various reasons (1996:144). By assessing the specific use of social support services in the Kansas City area, this project hopes to identify trends that may be relevant to other communities with similar characteristics.
City area, this project will collect data about the type of programs used by patients, the frequency, and the perceived benefit of different types of services on the patients.

Most studies in the past have evaluated how cancer patients are socially-supported after the completion of treatment. I believe that my study is unique because it evaluates the social support of patients during the treatment process, and the psychosocial effect of those services on the patient. My research study is not using complex methods to quantify the mental status of the patient. Instead, the survey asks about the importance of the social services for the patient, whether the service helps the patient cope with the cancer treatment, and what type of “support”—emotional, physical, spiritual, financial, social, psychological, or other—that the social support services offer to patients who use them. According to a multi-study review by Hegelson and Cohen, cancer patients identified “emotional support” is the most helpful kind of support during the disease process (1996:136). However, I believe patients who use social support services will identify “physical” support as another important type of support, especially during the cancer treatment. Ultimately, an analysis of the data from the surveys will show: how many patients use social support services during treatment; if those services are helping them to cope with the cancer treatment; and what type of support those services provide to the patient.

Personal Motivation
As an undergraduate, I majored in Medical Anthropology at Southern Methodist University and therefore developed a strong interest in the humanistic side of medicine. For an undergraduate thesis in 2007, I completed a research project in Ecuador and Costa Rica through the Richter Fellowship program that resulted in publication of the results. My project entitled, “Environmental Volunteer Organizations: A Vehicle for Economic Sustainability,” evaluated the effect of volunteer organizations on the economic prosperity of the surrounding, local communities. The project involved interviewing community leaders in the rural areas of Ecuador and Costa Rica in order to gain their perspective about the growth of the international volunteer organizations in their villages. Although it was not medically-related, this ten-week experience taught me how to develop a research project properly, how to execute it, and especially how to adapt when plans change.

Personally, I developed the idea for this project because of my strong interest in the psychosocial needs of patients with chronic illness. I am particularly interested in cancer patients because I would like to be an oncologist in the future. I developed my strong interest in oncology after I began volunteering in October 2009 for a local nonprofit agency called Cancer Action. As a volunteer driver for Cancer Action, I transport patients to-and-from appointments because they do not have someone to transport them. It is one example of a social support service that helps to ease the burden that cancer patients feel while are undergoing intense medical treatment for their disease. Another example is when I volunteered for the SolarisCare Cancer Support Center in Perth, Australia, for four months back in 2006 as an undergraduate study-abroad student. The Center is physically located in the middle of the Sir Charles Gairdner Hospital, a major public teaching and research hospital in Perth. The Center is a volunteer organization that is supported by the hospital but funded by community donations. It was founded by an Australian oncologist, named Dr. David Joske, for the specific purpose of providing various means of supportive care to all people with cancer, their families, and caregivers. Supportive care services include: meditation, counseling, expressive art therapy group, massage therapy, Reflexology, Reiki, and others. With the patient-centered model of healthcare today, more importance is being addressed by healthcare facilities to address all the needs of the patient. I believe that the Solaris Cancer Support Center is an excellent model for how social support services can be integrated into mainstream medical care for cancer patients.
I have a sincere desire to passionately pursue this project with great zeal and earnest for the benefit of the psychosocial needs of cancer patients. After spending hours reading the Clendening Fellowship proposals from the previous five years, I became feverishly excited about the possibilities of my project. The Clendening Fellowship offers an extremely unique opportunity to earn funding for a project that I believe will set the stage for future research in the Kansas City area and places like SolarisCare Cancer Support Center in Perth, Australia. As a possible extension to this project in the future, I would like to research the differences between the delivery methods of social support services in Kansas City compared to a place like SolarisCare. I am already excited at the possibility to expand this research idea in the future.

With so many previous Clendening projects that performed research in other countries, I believe that my project has an extraordinary opportunity to make a real impact on the lives of local citizens in the Kansas City area. With the high prevalence of cancer and a true need for awareness about social support services, all of the nonprofit agencies expressed excitement about the project. All of them were truly surprised that a medical student would be conducting it! In addition, the Kansas City Cancer Center is very interested to learn the results of the project. Currently, they do not employ any social workers to assist their patients with social support services; however, they suggested that the results might convince them to incorporate social workers into their staff. Most importantly, I believe that the results of this project can aid the University of Kansas by improving the services and direction that they offer to their patients, in regards to social services. Ultimately, through my research and eventual publication, I hope to bring even more awareness to cancer patients undergoing treatment about the available support services.

**DESCRIPTION**

Project Coordinator: John Hunninghake
Faculty Mentor: Dr. Sarah Taylor, M.D.

<table>
<thead>
<tr>
<th>Specific Aims</th>
<th>Methods</th>
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<td>(1) Distribute surveys to cancer patients over a 16-week time period.</td>
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<td>(2) To evaluate how social support services help patients during their treatment</td>
<td>(2) Conduct structured interviews of cancer patients with the exact questions from the survey.</td>
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<td>(2) To increase awareness about the social support services available to cancer patients.</td>
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My project intends to answer the following questions:

1. Do patients use social support services while they are undergoing treatment? If so, which one(s)?
2. What services or programs do patients consider as “social support services”? What agency or organization provides those services?
3. What services or programs are used the most by patients? Why?
4. If patients use social support services, do those services help the patients cope with the burden of cancer treatment?
5. What social support services do patients wish would be offered?
Specifically, the survey and the interview components of this project intend to:

- Identify the **number of cancer patients** who use nonprofit agencies for social support services
- Identify **where** patients receive their services, and **why/how** that agency was chosen/discovered
- Identify what **programs and services** that local cancer patients consider as “supportive” during their cancer treatment process
- Identify the **most utilized** support services by cancer patients
- Identify **why** patients use one support service rather than another
- Identify the **perceived** effect of support services on the patient’s **quality of life**
- Identify the **importance** of support services to patients
- Identify the **type of support** that patients receive from social support services
- Identify **additional support services** that could be beneficial to patients
- **Indirectly acknowledge the existence of the available social support services in the KC area**

An analysis of the statistical patterns in the surveys intends to:

- Identify the **main sources** of social support in the Kansas City area.
- Correlate the **patients’ perceived benefit** of the support services with the **type and frequency** of services used by the patients
- Provide **useful data** to nonprofit agencies and healthcare providers for planning new initiatives, refining existing programs, and targeting materials to specific healthcare groups.
- Assess how well cancer patients’ **social needs** are being met

**Project Goals:**

- Sixteen-week timeline for survey distribution (March 29 – July 26, 2010)
- At least total 1000 survey responses (n = 1000) in order to reduce error and account for variability [Average of 10 completed surveys per week per clinic (8 total clinic locations among the KU Cancer Center and the KC Cancer Center locations)]
- At least 150 patient interviews total - average 5 interviews/day at each clinic (8 total clinical locations) for 32 days
- Clendening Project Presentation
- Write an article to for local and possible national publication

**Hypotheses:**

- “Counseling” will be the most used form of a social support service by cancer patients, which is consistent with the research (Murphy735:2004).
- Patients who use social support services will identify “emotional” and “physical” support as the most important types of support during medical treatment.
- Patients who participate more in social support services believe that coping with the burden of cancer treatment is easier for them than patients who do participate less in social support services.

**8-Week Project Timeline:**
March 8-12, 2010 (**does not count toward project time**) - Continue to interview physicians, social workers, and nonprofit agency representatives to refine the content of the survey
March 29, 2010 – Official beginning of survey distribution (pending HSC approval); cancer clinics begin asking patients to voluntarily complete the survey, starting at 8am.

May 10-28, 2010 (3 weeks) – Begin patient interviews at clinical locations; Verify distribution of surveys at the various clinics; Mid-project statistical analysis of survey results at 3 weeks

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<tr>
<th>Date</th>
<th>Action</th>
<th>Location Details</th>
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<tbody>
<tr>
<td>May 14th, 2010</td>
<td>Pick up completed surveys from the survey collection container at each clinical location.</td>
<td></td>
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<tr>
<td>May 28th, 2010</td>
<td>Pick up completed surveys from the survey collection container at each clinical location.</td>
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May 31-June 25, 2010 – Air Force Commissioned Officer Training

June 28 - July 23, 2010 (4 weeks) – Patient interviews; Verify distribution of surveys at the various clinics by calling the representative of each clinical location

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<tr>
<td>June 28th, 2010</td>
<td>Pick up completed surveys from the survey collection container at each clinical location.</td>
<td></td>
</tr>
<tr>
<td>July 12th, 2010</td>
<td>Pick up completed surveys from the survey collection container at each clinical location.</td>
<td></td>
</tr>
<tr>
<td>July 23rd, 2010</td>
<td>Official end of survey distribution; at 5pm, cancer clinics stop asking patients to voluntarily complete the survey</td>
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<tr>
<td>July 26th, 2010</td>
<td>Pick up survey collection containers from each location.</td>
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July 26-30, 2010 (1 week) – Compile data, analyze, and complete the final report with the survey statistics. Begin full analysis of research data with the intention of eventual results’ publication.

**METHODS**

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The main methodology of this project is the **distribution of a survey** to eight different cancer clinic locations around the Kansas City metro area. The locations of the local cancer clinics include: University of Kansas Hospital Cancer Center, Kansas City Cancer Center (7 out of 11 clinical locations—includes Central, East, North, Shawnee Mission, South, Southwest, and West offices; excludes Business Office, Blue Springs, Medical Mall, West Radiation is part of West Office). The clinics were chosen based on
patient volume, presence of two or more medical doctors, location, and an agreement to allow distribution of the survey.

The study is a non-interventional, epidemiological analysis where patients fill out a written survey or respond orally to questions about the type of support services that they use. With the statistical data, this project aims to correlate the type and frequency of services that patients use with the patient’s perceived effect of these programs.

The purpose of the written survey is to collect data about the use of social support services by patients who are undergoing treatment for cancer. “Cancer treatment” is defined as a current chemotherapeutic regimen, radiation, or a combination of chemotherapy and radiation. The survey will be distributed by the cancer clinics beginning March 29, 2010 and will cease distribution on July 26, 2010. Currently, I have gained initial approval from the Kansas City Cancer Center and University of Kansas Cancer Center to distribute the survey and conduct interviews at their locations. I am currently in communication with a representative from each clinic to develop a survey distribution procedure for the clinic. Each clinic will have a slightly different procedure for the survey distribution and interview conduction depending on its setup and arrangement. In general, the front desk employee will ask each eligible patient for voluntary completion of the survey. An eligible patient means that he or she is present at the clinic for cancer treatment, and not present at the clinic as a “new patient.” If an eligible patient asks questions about the survey before beginning, the patient will be handed the cover sheet for the “Consent Form” to explain the project. After voluntary completion of the survey, the patient will personally place the survey through a slit in a designated secure container in order to protect patient privacy. Data collection will begin on March 29, 2010. I will collect the surveys from each clinical location every two weeks in order to protect the information on the completed surveys and to assess the amount of completed surveys. The surveys will be collected from each clinic every two weeks beginning May 14, 2010, and continuing on the dates of May 14, May 28, (not June 11 due to Air Force training), June 28, July 12, and July 26. The data collection period will close on July 26, 2010.

In addition to the survey, patient interviews will be conducted. The purpose of the patient interviews is to ensure proper completion of the surveys and to increase the number of completed surveys. I will spend four days at each clinical location, for a total of 32 days of patient interviews among the eight clinical locations. I will ask each eligible patient who is checking in for an appointment to verbally complete the survey in a private exam room. If the patient agrees, I will have them sign the “Consent Form” (please see the Appendix for the form). In the private room, I will ask the exact questions that on the survey and then mark the answers on the survey. I will not ask any additional questions that are not on the survey. I will not write any additional physical information about the patient on the survey. I will not physically examine the patient in any way. Upon completion of the interview, I will have the patient visually verify the answers on the survey, and then sign a designated line on the “Consent Form” indicating that they verified the survey. Ultimately, the interviews are intended to ensure adequate completion of the survey and to increase the number of completed surveys. An increased number of completed surveys will help reduce variability and error in the final research statistics.

I have currently submitted an Application for Exempt review to the IRB Human Subjects Committee. According to the IRB Administrator, Dan Voss, the committee is currently busy with applications and it will take about 10 days for approval. However, Dan Voss has reviewed my survey questions. He believes that my survey is low-risk and states, “None of your questions raise any red-flags of which the IRB would be concerned.” Additionally, I have submitted an application to the University of Kansas Cancer Center IRB committee, and am currently awaiting approval.
Approval, Permission, and Endorsements
The University of Kansas Cancer Center has agreed to allow the distribution of the survey and the conduction of interviews at their Cancer Center, pending official approval from the Cancer Center IRB Committee. I have been in contact with the Executive Director, John Hennessey, of the Kansas City Cancer Center about approval to distribute client surveys on seven of their ten clinical locations. He forwarded on the survey to his Compliance Officer for official approval, but has given unofficial permission assuming that there are no complications with his Compliance Officer’s review. Two social workers at the KU Cancer Center, Jan Peterson and Mary Moody, have reviewed my survey. They both agree that the survey will collect valuable information that “could greatly benefit cancer patients and the community-efforts to assist them.”

With regards to the nonprofit agencies in the community, I have received an overwhelming response of positive support. I have received permission to use Turning Point in my survey from Moira Mulhern (CEO of Turning Point) and Cindy Raedle (the Director of Community Outreach at Turning Point). They have both strongly endorsed the project. I have also received approval to use Cancer Action in my survey from Karla Nichols (the Executive Director at Cancer Action and the Director of the Cancer Coalition in Kansas City). I have spoken with Vangi Rich, the Executive Director at the R.A. Bloch Foundation, and received approval to use them in my survey. Sandy LeRoux, who is the Director of Community Affairs at the American Cancer Society chapter in Kansas City, has reviewed my survey and given me permission to use the organization in the survey. I have contacted the National Cancer Institute, and am currently awaiting a response. All the directors that I contacted were unanimous in their support for the research study; they believe it will gather valuable data that can be used to further the collaboration of local agencies in offering needed support services to cancer patients.

BUDGET
Printing costs for the survey, informed consent page, and other documents
- 2 pages per survey * 1000 copies = 2000 pages * $.05/page = $100
- 2 pages per informed consent * 200 copies = 400 pages * $.05/page = $20
1 box/ clinical location * 8 locations * $5/box = $40

Transportation - travel to and from local cancer clinics
- Survey distribution/pickup = $5/day in gas * 5 days = $25
- Interview days=$5/day gas * 32 days = $160
June and July Rent in Kansas City = $700/month x 2 = $1400
Food/groceries for 8 weeks = $600
Research Material (books)
- “Cancer Care for the Whole Patient” by Nancy Adler and Ann Page = $42.26
- “Anticancer: a new way of life” by David Servan-Schreiber = $19.00

Total Budget Costs: $2406.26

I understand that the Clendening Fellowship will not be able to cover all of my project and living expenses during the eight weeks of the research study. If I am accepted for the Clendening Fellowship, I plan to use my savings to supplement the remainder of the budget costs. I would greatly appreciate the experience that Clendening has the chance to offer me, and would be very grateful for the opportunity to explore this important social issue for the sake of the patients!
Contact Information

Dr. Sarah Taylor, M.D. (faculty mentor)  
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Sandy LeRoux  
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Jan Peterson and Mary Moody  
Social Workers  
University of Kansas Cancer Center  
913-588-4776 and 913-588-3630  
jpeterso@kumc.edu and mmoody@kumc.edu
BIBLIOGRAPHY


Matthews, B. Alex “Oncology professionals and patient requests for cancer support services.” Support Care Cancer (2004) 12:731-738


List of Participating Agencies and Cancer Clinics in the Kansas City Area (to be handed out to patients who ask for more information about local social support services)

Local and National Nonprofit Agencies (listed in alphabetical order):

**American Cancer Society**
[www.cancer.org](http://www.cancer.org)
1-800-ACS-2345

**Cancer Action**
[www.canceractionkc.org](http://www.canceractionkc.org)
913-642-8885

**National Cancer Institute**
[www.cancer.gov](http://www.cancer.gov)
1-800-4-CANCER

**R.A. Bloch Cancer Foundation**
[http://blochcancer.org](http://blochcancer.org)
1-800-433-0464

**Turning Point**
[www.turningpointkc.org](http://www.turningpointkc.org)
913-383-8700

Local Cancer Clinics:

**Kansas City Cancer Center**
[http://www.kccancercenter.com/support-resources/overview/](http://www.kccancercenter.com/support-resources/overview/)

**University of Kansas Cancer Center**
[http://cancer.kumc.edu/](http://cancer.kumc.edu/)
913-588-1227