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The purpose of this study is to provide a complete description of the UNC Cancer Center's Patient and Family Resource Center in its context through an analysis of qualitative comments from interviews with the Center administrators, a health sciences librarian, healthcare professionals and Resource Center users (n=10). These perspectives offer unique information about the provision of consumer health information from providers and users of cancer information.

The interview data gathered about the Resource Center answers questions about how consumer health information is provided, and how the Resource Center is meeting established goals of informing and teaching consumers while promoting positive interactions between patients and medical staff within the Cancer Center. The data also addresses future improvements regarding what resources are lacking, and how the services offered can be extended or improved.

Headings:

Health -- Information Services

Cancer -- Information Services

Patient Education

Hospital libraries

PATIENT EDUCATION AND CONSUMER HEALTH INFORMATION: A STUDY
OF THE PATIENT AND FAMILY RESOURCE CENTER AT THE UNC-CH
CANCER CENTER

by
Lindsey Ritter

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Approved by

Dr. Claudia Gollop

Introduction

Consumer health information and its importance to the public have been extensively researched and it currently receives great attention in the context of libraries and patient education centers (Gillaspy, 2000). The last twenty years have seen a change in health care with people taking active roles in their health and in the health of their families (Longe, 1998). Consumer health information was recognized as a legitimate and growing concern by the early 1970s, and the American Hospital Association expressed the patient's right to be informed in its *Patient's Bill of Rights* (Huber & Snyder, 2002). According to Deering and Harris (1996), consumer health information includes: medical instructions and decision support information, health and self-care information and education, quality-in-care information and alternative or complementary medicine. Huber and Snyder (2002) divide consumer health information into five broad categories including information on drugs and disease, coping, health care and medical ethics, prevention and wellness and normal bodily functions. It has become increasingly important for public and hospital libraries to provide access to reliable sources of health information on a local and easily comprehensible level. Librarians have taken on some of the responsibility of sorting through massive amounts of electronic information in an attempt to find and promote what is useful, readable, current and accurate for the patron's ease and use.

A major health concern for many people and their families is cancer. According to the North Carolina Central Cancer Registry, cancer is the second leading cause of

death in North Carolina and in the United States. In 2005, 16,673 people died of cancer in North Carolina.¹ Dealing with cancer is a difficult reality faced by many, and therefore the provision of accurate and reliable consumer health information on this topic is an important need. This study examines how the Patient and Family Education Center at UNC's Comprehensive Cancer Center operates in the hospital context, and how it meets the information needs of cancer patients and family with staff and resources.

According to Kernaghan (1991), three goals of resource centers include to inform, to teach and to promote the hospital. Informing includes providing easy to understand health information, teaching involves self-care and coping, and promoting the hospital is the encouragement of positive relationships between patients and medical professionals. The interview data gathered from Resource Center users, health care professionals and administrators will help to determine how consumer health information is provided, how the Resource Center is meeting these established goals of informing and teaching consumers and promoting the hospital; along with what resources are lacking, and how the services offered can be extended or improved.

Review of Literature

The following literature review addresses a variety of specific aspects regarding consumer health information and looks at research aligned with the perspectives addressed in this study, which include resource center operations, collaboration between health sciences libraries and hospital resource centers, consumer health information and

physicians, and how patients use consumer health information in their own care and treatment.

Consumer health information is not a new concept, as patients and their relatives have met to exchange information and support each other throughout history in an attempt to understand and deal with various diseases and illnesses (Gillaspy, 2000). Hospitals in the United States have also provided medical libraries for patients since the nineteenth century (Huber, 2002). However, in recent years the provision of consumer health information has changed for many reasons. Two major changes have been due to the large amount of new biomedical information available, and the advent of improved communication and information exchange with the Internet and World Wide Web (Gillaspy). These two changes have had positive and negative effects. On the one hand, information is more prevalent and accessible. On the other hand, the large amount of available information can be overwhelming and is not always the best quality. Therefore, it has become a growing need for libraries and health care professionals to work together through patient resource centers in an attempt to organize and provide the best health information to patients and families.

Other reasons for an increase in the demand for consumer health information include a “constantly mobile population with frequent changes in doctors, managed care which requires people to take more responsibility for preventive care and health, a fitness lifestyle, patient activism, medicine in the news, and advances in biotechnology and genetics” (Gillaspy, 2000). Electronic media provides accessible and ever-growing resources to the public on numerous health topics including nutrition, exercise, and how to care for colds, the flu and ankle sprains (Longe, 1998). Because the public now

chooses to acquire more comprehensive knowledge about health care issues, it is an important responsibility for health sciences librarians to respond to the public's need (Calvano, 1991).

So, how is consumer health information delivered to the public? Public libraries and patient education centers have recognized the demand for consumer health information and have taken on the responsibility of providing accurate and reliable educational materials on health for the lay user. Patient education centers also have many opportunities to improve health through planned and structured information delivery and education, referred to as the "wellness continuum" or natural history of disease (Longe, 1998). Specific ways to convey information and support include access to computers and the web, books, consumer health web pages, bulletin boards, discussion groups, "ask an expert," "ask a librarian," personal stories, a referral directory, health charts and decision aids (Longe). Other resources offered could include web casts, blogs for patient to patient communication and support, interactive web tutorials, and videos.

The importance of Patient Resource Centers is evident in their ability to provide accurate and accessible health information, along with resources and activities devoted to health promotion. The delivery of health information to the public is often facilitated by partnerships between academic health sciences libraries and public libraries or patient education centers. The development of consumer health centers within hospitals demonstrates patient participation in not only diagnosis and treatment, but in the understanding of their own health outside the physician's office (Kernaghan).

Kernaghan (1991) outlines several reasons for the development of these Resource Centers:

- The cost restrictions that government and business have imposed on in-hospital stays and the resulting decrease in time to inform and teach inpatients
- The increasing number of ethical decisions that require patient/family involvement
- The expanding number of acute, long-term, and ambulatory care settings that fractionalize the continuity of care and complicate consumers' ability to understand and efficiently use the system
- The substantial likelihood that patients have incurable, chronic conditions that require their understanding and their active participation in the course of treatment and management
- The technical nature of much of the health-related information that is available, the lack of up-to-date, complete, and accurate lay materials, and the lack of services to help consumers find appropriate information amid a bewildering array of informational resources that are often produced by popular press and others who offer products and services of a dubious nature
- Hospitals' legitimate self-interest in being visible and positive forces in their communities

Three goals of these centers include to inform, to teach and to promote the hospital (Kernaghan, 1991). Informing involves “supplying current information on health, disease, and wellness in language and by media that consumers can understand and use” (Kernaghan). Teaching “provides opportunities for consumers to learn the skills of self-care, self-management, and coping.” The last goal is hospital promotion which “offers information that will help consumers make better and more positive linkages with the hospital, its medical staff, and other health care providers” (Kernaghan). These goals provide the framework for my research and help guide interview questions to determine how these goals are being met. The many components of patient resource centers work to meet these goals. Kernaghan lists these typical components starting with range of services, which includes: a collection of health materials in the form of books, pamphlets, current periodicals and audiovisual materials,

a way for consumers to access the information, and a way for consumers to be referred to other sources of information.

Other components include the placement of the resource center within the organizational structure, the physical location of the center inside or outside the supporting institution, financial support sources, staffing, and collaboration between the center and outside libraries and community agencies (Kernaghan). All of these typical characteristics will be examined through data from structured, open-ended interviews.

According to Longe (1998), “Employers and health agencies dedicated to one condition (heart, cancer, etc) can be successful in choosing to offer a narrow portion of the continuum for their constituents,” and this success depends on having a good understanding of the information needs and best modes of delivery for the people and patients they serve.” The provision of consumer health information can also have an impact on shared decision making which joins physicians and their patients in the decision making process and allows patients’ preferences to be incorporated into clinical choices (Coulter, et al, 1998).

One important service of a Patient Education Center is the ability to provide consumer health information through an expert searching service. Information that is not readily available in books, brochures, etc, and requires an extensive Internet search or search in a database is considered expert searching by the librarian. The expert searching service attempts to “help patients understand their illness and treatments, help them make informed treatment decisions, improve their quality of life, and facilitate a productive dialogue between patients, caregivers, and clinicians” (Volk, 2007). According to a study done on expert searching in consumer health information at The

Patient Education Resource Center at the University of Michigan Comprehensive Cancer Center, 96.2% of users indicated that the professional searches provided them with information that they would not have found on their own. The response from users was very positive with 83.4% indicating that the service was excellent (Volk, 2007). Volk's study shows the importance of providing users and their families with information they could not find alone and describes the usefulness of consumer health information in a patient education center context. Users in the study found the service helpful, and the information provided to them may have a further impact on health decisions.

Burnham and Peterson's 2005 case study research highlights the importance of health literacy and how libraries can collaborate with community organizations in order to increase health awareness and understanding. The research examines the goals, purpose, collection, and operations of a Neurological Disorder Patient Resource Center through a case study (Burnham & Peterson). The abbreviated mission is to provide health information to patients, families, care givers and the general public to help them become informed, active participants in their own care. The goals include: "providing patients, families and caregivers access to reliable consumer health information, creating awareness of these issues among hospital staff, advocating and promoting the patient's right to confidentiality and access to medical information, and working with the hospital staff to create patient education materials" (Burnham & Peterson). The case study research revealed that these goals are met through the translation of medical terms into lay terms for users, links to quality resources from the web page, answering phone and email questions, distributing pamphlets, information sheets and books for

patients, and providing information on diagnostic tests, clinic handbooks, caregiver guides, and fact sheets on particular conditions created in collaboration with medical professionals (Burnham & Peterson).

Recognizing the importance of health education and a relatively low adult literacy rate and thus low health information literacy, this research examines the significance of providing authoritative, current and consumer-driven health materials that can explain difficult medical terminology (Burnham & Peterson). Defined by the Medical Library Association in 2003, health information literacy is "the set of abilities needed to: recognize a health information need; identify likely information sources and use them to retrieve relevant information; assess the quality of the information and its applicability to a specific situation; and analyze, understand and use the information to make good health decisions" (MLANet, 2003). This research is important and relevant because it examines the organization of a Patient Resource Center through a case study and identifies how it meets the goals of providing consumer health information and improving health literacy through services and collaboration.

Another study done at Crouse Hospital in Syracuse, New York looked at the development of a patient education task force and multidisciplinary collaboration (Tarby, et al, 1997). According to Tarby, et al (1997), "the primary mission of hospital libraries is to develop programs and services that provide information to a focused customer base."

A 1994 study done by the Oakwood Hospital Library documented health information needs and opinions among health consumers and physicians. The study examined consumer need, where physicians referred consumers for further information,

how successful consumers were in finding needed information, and whether and to what extent a consumer health information library would be valuable (Phillips). Opinions were elicited through surveys to a physician group and a consumer study group. The survey questions focused on the physician's or consumer's role in the information process and also compared physician and consumer viewpoints with identical questions included in both surveys. The results showed that 44% of physicians considered access to appropriate health information to be a problem, 91% of physicians said they would refer patients to a hospital-operated consumer health library, and 88.7% said they would request resources from the consumer health library for their patients. Results for consumer opinion showed that 69% of respondents considered finding appropriate health information to be a problem, and 92% reported that they would use a consumer health library if Oakwood opened one. Around one-third of respondents said they would like to see consumer health information at their local public library and 46% said they would use a hospital facility or off-site location (Phillips, 1994). The data suggests that physicians and patients support hospital operated consumer health libraries and deem them helpful in physician/patient communication. Increased knowledge can lead to more effective communication between physicians and patients and can have an impact on care decisions.

Shared decision making between patients and physicians on care and treatment options is receiving more and more attention. Data suggests that the active involvement of a patient in his or her treatment decisions can increase the effectiveness of the treatment (Coulter, et al, 1998). A study done by Coulter, Entwistle and Gilbert (1998) examined the needs of patients with specific conditions and found that most patients

wanted much more information than they were given. The patients in the study reported that an increase in information about their condition and treatment would help them communicate more effectively with their physician, and thus possibly impact a treatment decision. Specifically, patients said they were not receiving enough information on the natural history of the conditions from which they suffered, and were less equipped to cope with their health situations (Coulter, et al, 1998). This study suggests that an increase in appropriate and complete information for patients can help them effectively communicate with physicians in an attempt to understand and then decide on the best treatment options.

Pifalo, Hollander, Henderson, DeSalvo and Gill (1997), completed a study on how consumer health information impacts the individual user. The study looked at how consumer health information was used and how it affected consumers' knowledge, actions and feelings in areas of personal health concerns. The study findings indicate that almost all users (94%) found that the information increased their knowledge about an illness or health concern. Nearly half reported that they were better able to understand information given to them by their health care professional. Users who completed the survey also reported that reading about health information decreased anxiety concerning an illness or personal health issue, had asked questions of their health care provider, and made treatment decisions based on the information (Pifalo, et al., 1997). Other responses regarding use of the information included the decision to make a lifestyle change, follow instructions from a health care provider, seek a second opinion, and make an appointment with a health care provider. Three respondents reported that the information had no effect on them. Satisfaction with the service was

evident in that all but one respondent indicated they would use the service again and recommend it to others (Pifalo, et al., 1997).

The data collected by Pifalo, et al. suggests that consumer health information has an impact on consumers' knowledge, actions and feelings regarding personal health issues. The majority of users were able to use consumer health information to increase their knowledge, communicate more effectively with a health care professional, decrease anxiety about an illness and make a treatment decision.

Methods

The method for this research is a descriptive study of the Patient and Family Resource Center at UNC's Comprehensive Cancer Center that presents a complete description of the center within its context (Hancock & Algozzine, 2006). This study is an empirical investigation of the Patient and Family Resource Center using structured, open-ended interview data from multiple perspectives. The purpose of the interviews is to examine how services are provided and how the Center operates based on qualitative comments from the perspectives of the Center's administrators, a Health Sciences librarian, Resource Center users, healthcare professionals, including oncology nurses, a registered dietician, a radiation oncologist, and the Center founder (n=10).

Potential participants with knowledge of the Center and its use, or key informants were identified by a Center Administrator. Non-probability, purposive sampling was used in this study because the interview participants have characteristics of a particular subgroup of interest, in this case knowledge of, or experience with, the provision of consumer health information in a hospital setting, with the sample also

facilitating comparisons (Babbie, 2004). The interview participants have been chosen because they have the potential to offer information on the Center from different perspectives and have knowledge and experience with the Center.

Potential participants were contacted by email and asked to respond to the researcher if interested in participating. Interviews were conducted in person with the ten consenting participants. The interviews lasted between forty-five and sixty minutes and were conducted in closed offices in the hospital. The content of the interview questions are included in Appendix A. The questions were written to address the areas identified by Kernaghan: consumer health information, how the resource center informs and teaches the public, how the resource center promotes the hospital, and how the resource center can be improved. All participants were asked these questions in order to gather information on the resource center from multiple viewpoints.

Conducting interview research involves important ethical considerations. Maintaining patient confidentiality is an ethical issue in this study and no personal or sensitive information was revealed, and the participant's names were kept confidential (Babbie, 66). Consent to participate was gathered through a consent form which was approved by the UNC Institutional Review Board (IRB) (See Appendix B). Data was stored on a password protected laptop, only accessible to the researcher and one advisor.

Data Analysis

In analyzing the interview data, the fundamental research questions were kept at the forefront and less relevant data was left out as a way of managing the large amount

of qualitative data gathered (Hancock & Algozzine, 2006). The relevant data was then separated into the four major categories that respond to the research questions. The categories include informing the public/providing consumer health information, teaching the public, promoting the hospital and improvements. Informing the public/providing consumer health information is defined by Kernaghan (1991) as “supplying current information on health, disease, and wellness in language and by media that consumers can understand and use.” Teaching the public includes, “opportunities for consumers to learn the skills of self-care, self-management, and coping” (Kernaghan, 1991). Promoting the hospital includes how the Resource Center “offers information that will help consumers make better and more positive linkages with the hospital, its medical staff, and other health care providers” (Kernaghan). The last category involves ways the Resource Center can be improved as it moves into the future. The data was then examined using Kernaghan’s guidelines, and all the items of data assigned to the same category were compared and contrasted so that trends could be identified across multiple perspectives (Sapsford & Jupp, 2006). The data was summarized to provide a description of the Center and how it meets Kernaghan’s (1991) suggested goals.

Findings

Resource Center Background

The Patient and Family Resource Center is the keystone of support for patients at UNC’s Lineberger Comprehensive Cancer Center. According to their website, “....a team of counselors, a chaplain, and trained staff work with patients and families

throughout their cancer experience...Complementing staff services is an extensive lending library and free educational and support materials to help families understand their cancer diagnosis and treatment. Resource Center staff meets individually to tailor information needs of patients and families.”² Center administrators describe it as place to get away from the mainstream, and similar to a relaxing “living room.”

The Patient and Family Resource Center opened in 1991 after administrators felt it was necessary to have a place to meet the informational and emotional needs of cancer patients. The hospital had an inpatient education center but nothing for outpatients. One administrator commented that, “UNC is a comprehensive cancer center, what you have to do is excellent lab research, clinical care, population science research and training. Under patient care comes patient education, which is a very important part of the entire treatment, where we take care of the patient’s mind and body, a place where we can focus on that, which is a critical component of being a comprehensive cancer center.” The Center founder had great vision as a patient advocate to see the need for an area with resources in the midst of what was then only medical treatment.

Because the Resource Center opened in pre-Internet days, it offered books and videos to users, along with programming on nutrition, beauty, coping with therapy, doctor/patient communication and support groups. These programs continue today and the Center now has a public computer with Internet access. The Center was also opened because of frequent calls from patients who found the public library to be lacking in the information they needed. Locating the Center in close proximity to where patients are

treated helps to take the information directly to them. The Resource Center is open to the general public and all services are free of charge.

The Center is staffed by two administrators who manage the collection and plan and promote education and wellness programs. The Center's overall purpose is to make cancer patients and their family's journey through treatment easier. More specifically, one purpose of the Resource Center is providing patients with information on diagnoses, treatments, surgeries, coping, exercising, how to talk to their doctor, and setting up appointments with counselors and chaplains. The second purpose involves outreach programs that "reach out to the heart" and help with self care and coping. A Center user commented that the Resource Center operates on two levels, one is through books and the Internet, and the other is through programs and outreach. These purposes align with Kernaghan's goals of informing and teaching the public.

Informing the Public

Providing current health information that is easy to understand is the basis of informing the public. The collection in the Resource Center includes books on nutrition, coping, death, alternative and complementary medications and therapies, spirituality, information for prevention and information on understanding medical terminology. There are also numerous informational brochures on all types of cancer, cancer treatments, sensitive topics and information in Spanish. The most useful resources for Center users come from the nutrition collection or the brochures because they are easy to pick up and take home. Center administrators agree that the informational brochures are frequently picked up, and estimate that 99% of people who

come in take at least one brochure home. This is especially helpful when users want to find information without having to ask sensitive health questions. Those who use the Resource Center vary greatly in terms of economic and educational level and service provided to users has to be individualized depending on learning style, disease, sex, race, access to the Internet and level of education. Those who staff the Resource Center are required to conduct reference interviews in order to determine and meet the requests of users. Information is packaged differently in different forms, so it is important to get to know the user and decide what they need.

An important part of informing the public is catering to health information literacy skills. Center users find the information straightforward and easy to understand. The resources specifically focused on cancer are on a level between fifth and eighth grade. Many of the resources come from the National Cancer Institute and the American Cancer Society and both follow guidelines for patient education. Administrators explain that these resources provide easy to understand information on cancer. A lot of Center users are at an estimated fifth grade reading level and are not able to use computers, so the Resource Center is there when extra assistance is needed. Because the Center provides a comfortable environment, many users let administrators navigate the Internet for them in order to find the best customized information. Center administrators and health care professionals agree that information overload can be a problem and know that Center users need direction when searching. A Center administrator commented that although the immediacy of the Internet is convenient, nothing replaces the hard copy resources they have on general cancer information like chemotherapy and radiation treatments. The daily activities vary as much as the users

do, and one important goal of the administrators is to provide what the user needs at the point of care, whether for those with a recent diagnosis or those with a dramatic change in condition. The administrators work to provide information that is very individualized to the user's needs.

Health care professionals are also required to determine information needs and tailor what is provided to the particular patient. In terms of providing easy to understand information, health care professionals commented that it is very hard to bring difficult science down to an understandable level for patients, although it is easier to find current information on a patient level with the Internet. Most health care professionals interviewed feel that patients trust the information they are given. Because of the breadth of information at the Resource Center, the administrators and health care professionals can tailor the information given to the patient in a way that is the most helpful to them.

All of the health care professionals interviewed think that the Resource Center is providing an important service in terms of consumer health information and is a fundamental part of patient care; however, there are mixed thoughts on how consumer health information is provided in hospitals. One health care professional commented that the hospital in general does not provide any information on better nutrition or how to prevent cancer, and that is why the Resource Center is very important. He also described how information provided to patients has changed in the health care field. In the past, physicians made a diagnosis and did not offer any options to the patient. Today, patients are much more involved in their own care and in making treatment decisions, and therefore conduct much more research on their conditions than in the

past. Across the groups interviewed, most regard the Internet as the main source for consumer health information, although health care professionals observe that there is a great disparity in the amount of information that patients are gathering from the Internet. Some patients do little or no research and others bring in numerous pages from web sites.

The Resource Center also collaborates with the Health Sciences Library for expert searching. A health care professional commented that librarians have to make important and knowledgeable judgments without being judgmental. When Center administrators are unable to meet the information needs of a user, they refer the question to the Health Sciences Library. Questions are frequently about the latest research, information or nutritional, supplementary, and complementary therapies for specific cancers. Less frequent questions involve recommendations for relaxation and entertainment resources. The information is given to patients and families to assist with making decisions about treatments and therapies and ways to cope with the effects of treatments and therapies. The Health Sciences Library also suggests new resources for the Center.

Data trends across the groups in this section show that informing patients on an easily comprehensible level is extremely important, and this is supported by the Resource Center staff and collection. Health care professionals, Center users and administrators also agreed that information must also be tailored to meet the different needs of patients and this includes learning style, reading level, condition, amount of information desired, and access to the Internet and other resources.

Teaching the Public

Teaching the public includes information for self-care and management and how to cope with cancer. The UNC-CH Cancer Center is considered a comprehensive cancer center, and this distinction depends on many aspects of patient care including excellent education and outreach. The Resource Center offers many educational programs on preventive health which include informational sessions on the HPV vaccine, and sessions on self-breast exams and melanoma. Center administrators also attend health fairs in the main hospital, including Women's Health Day and provide educational materials on self-exams and cancer prevention.

Other programs like luncheons are opportunities for learning and normalization, addressing the patient's emotional side, and are not strictly educational. For example, the "Look Good, Feel Better" boutique provides hats and scarves to help patients deal with hair loss. The Resource Center also offers free classes on nutrition during cancer treatments taught by a registered dietician who works closely with patients. Health care professionals agree that the Resource Center does a good job of outreach, but would like to do more programs for outside communities. One-on-one teaching sessions are also done with health care professionals and patients on pharmaceutical information in order to explain medications and doses.

Another part of teaching involves coping skills. A health care professional stated that "[the Resource Center] is an important part of the general care of the patient; it deals with mental and spiritual healing, while physical healing is the conventional part." When a patient realizes the truth of his or her diagnosis, the Center can support them during this realization with information or by pointing to other services like the

Cornucopia House, a local cancer support center. Caregivers can also come in when they are scared, tired or need support and validation for their feelings. Health care professionals, Center users and administrators agree that Resource Center is providing opportunities for the public to learn more about self care, cancer prevention, and coping.

Promoting the Hospital

Promoting the hospital involves creating positive connections between consumers and the hospital and its staff. One health care professional describes the Resource Center as “one angle of the human face of the hospital institution, able to be warm and caring and a given and necessary program within a National Cancer Institute designated comprehensive cancer center.” A health care professional has heard patients comment that it provides more incentive to come here and provides more benefits to the patients. Health care professionals are also becoming more apt at connecting the hospital with the Lineberger Cancer Center and its research, and connecting with various cancer societies like the Lymphoma Society, for programs with nursing and social work staff oriented to patients, families and the public. The Center is able to provide a welcoming atmosphere with coping and quality of life information, and it is important that patients leave the treatment area with some level of satisfaction.

The Resource Center is also able to help with doctor/patient communication. One Center user said that using the resources and having the ability to look up information on a condition has helped in communicating with doctors. Center users receive guidance with using resources and are able to write down information to later address with doctors.

Improvements/ Future Considerations

As the Patient and Family Resource Center moves into the future, those interviewed were asked about improvements. All participants interviewed commented that the Resource Center should have more space. Six out of ten interviewed believe that the Resource Center should be located in a more prominent space, while four think it is in a good centrally located area for patients to use. One Center user commented that it took him a long time to find the Resource Center and wished he would have found it earlier because it has been a great help.

The four major goals of administrators are gaining more support, providing better individualized care, more outreach into surrounding communities, and the ability to do more research. Gaining more support involves seeking grant funding, outside donations and an increase in communication with the community and health care professionals. The other goals can be met in part with increased staff, and one Center administrator thinks the best solution for this is the active recruitment of volunteers who have experience with cancer and can empathize with Center users. Health care professionals and administrators listed many more specific goals for future improvements including more staffing like librarians and counselors, more computers, more programs like cooking classes outside the hospital, and healing touch events with massage, yoga, relaxation, complementary therapy and journaling exercises. Moving into the future, one expansion of program offerings and information will be on survivorship, and as science emerges, more programs on cancer prevention strategies and evidence based nutrition and therapies.

To meet the research goal, an administrator and a health care professional would like to conduct a programmatic needs assessment in order to determine how to best provide information and education to patients. Currently, there are encounter forms for users to fill out that ask: “how did we help?” and “what else can we do that would be helpful?” along with diagnosis and county of residence. These encounter forms are used to evaluate services and gather information for further outreach into communities outside UNC-CH. The Resource Center would also like to review programs to see what areas are lacking in support groups and also place more focus on breast cancer patients. Because the needs of patients will never decrease and diagnoses will continue to be complex, administrators look forward to growth and improvements that will better serve those who use the Center.

The Resource Center would also like to integrate information on general health issues like hypertension and diabetes into the collection, and also offer educational sessions to the community on four major areas: breast, colon, testicular, and skin cancer. All of the health care professionals agree that the Resource Center should become a part of the patient’s entire treatment, and that patients should be referred there just as they are referred to other doctors and specialists.

Center users also listed many goals for the future of the Resource Center including holding classes to help people search the Internet for health information, and programs for different types of cancer in order to build up support groups. More advertising in the community was also suggested as an important way to reach more people outside of the UNC-CH area. Everyone interviewed agreed that the Center has

provided a great service thus far and that more space and more resources will be key improvements for the future.

The Patient and Family Resource Center provides a great service to many individuals dealing with cancer personally, or through a friend or family member. The administrators work hard to provide information and emotional support that is customized to the individual. An administrator commented that the most incredible part of the job is listening to patient and family needs and then helping them meet their needs through various avenues of support. The health sciences librarian is a crucial part of the process and is able to provide the most recent and specified information to patients through expert searching. Health care professionals agree that the Resource Center provides the mental and spiritual healing that completes a patient's entire treatment. Center users commented that certain resources have changed their lifestyles, particularly with nutrition, and that they are now involved with support groups. Although staff and space is limited, Center users, the librarian, and health care professionals agree that the Patient and Family Resource Center is a necessary part of the total healing process.

Study Limitations

One limitation of this study is the small sample size, and although data was gathered from multiple perspectives, only a small number of people were interviewed which makes the results less generalizable. Conducting interviews allows for a great depth of understanding and validity, but the data is less reliable due to the personal nature of field research measurements (Babbie, 308). Other disadvantages of this study

are the possibly biased perceptions and recollections from the participants. Because the interviews gather qualitative rather than quantitative data, there are no statistically grounded descriptions of a large population (Babbie, 307).

For any future research done on this topic, it would be helpful to have a larger sample to interview with more participants from each group in the study (Center users, health care and information professionals, and administrators). Future research could also look at other Resource Centers in a comparative study instead of focusing on only one center.

Conclusion

In their 1997 study, Pifalo, et al. comment that consumers are very likely to continue to search for health information, and the number of consumers doing this will also continue to grow. Now, eleven years later, consumers are indeed continuing to seek more information in an attempt to better understand all the issues regarding personal and family health. As one respondent to their questionnaire commented, "The library is a very valuable service. It is essential to have a means to learn more about medical problems and conditions." (Pifalo, 1997).

As consumer health libraries move into the future, the public can benefit from evaluations of these library services, and how the acquisition of health knowledge can be further improved to impact patient care (Pifalo, et al, 1997). The data gathered from this research offers insights on consumer health information and how one Resource Center works to inform and teach users, while promoting the hospital and fostering positive interactions between the public and health care professionals. The findings integrate data from multiple perspectives presenting trends among the opinions of

Center users, health care and information professionals and administrators. The data also suggest improvements for the Patient and Family Resource Center as it moves into the future.

Notes

¹ North Carolina Central Cancer Registry. <http://www.schs.state.nc.us/SCHS/CCR/cp2007/Orange.pdf>. Accessed 24 September 2007.

² The Patient and Family Resource Center. <http://unclineberger.org/patient/resource-center.asp>. Accessed 28 October 2007.

³ The interview schedules for this research have been adapted from “Interview Schedule Sample Template” Accessed December 1, 2007, from <http://www.hawaii.edu/mauispeech/pdf/interviewschedule.pdf>

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Appendix A: Interview Schedules ³

Opening:

Hi, I am a Master's student at the School of Information and Library Science at UNC-Chapel Hill and I am doing a study of the Patient and Family Resource Center. I would like to ask you some questions about consumer health information and the Resource Center in the hopes of learning more about how the Center operates in the hospital context. I hope to use this information to benefit you and the Center. This interview should take between 45 minutes and 1 hour to complete. Please look over and sign this consent form (see Appendix B), and let me know if you have questions. Thank you for your time.

Interview with Center Administrators:

Body:

1. What is the purpose of the Patient and Family Resource Center? Role in the Cancer Center?
2. Describe the daily activities.
3. Describe the history of the Center.
4. How do patients and their families use the Center?
5. What resources are most useful? Beneficial? Most frequently used?
6. What resources are missing?
7. What is the Center's Internet presence?
8. Are there support groups available? Describe these.
9. How is the Center perceived in the hospital by doctors?
11. How does the Center meet the goal of informing the public? Is it successful in this? Explain.
12. How does the Center meet the goal of teaching the public? Is it successful in this? Explain.
13. How does the Center meet the goal of promoting the hospital? Is it successful in this? Explain.
14. What other goals do you see as relevant for the Center and its operation?

Interview with Health Sciences Librarian:

1. How does the Health Sciences Library collaborate with the Patient and Family Education Center?
2. Describe the expert searching service.
3. How do you see the Center operating in the hospital context?
4. What resources do you consider most helpful?
5. What resources do you frequently recommend?
6. Does the Health Sciences Library provide resources to patients?
7. How can services in this area be improved?
8. How does the Center meet the goal of informing the public? Is it successful in this? Explain.
9. How does the Center meet the goal of teaching the public? Is it successful in this? Explain.
10. How does the Center meet the goal of promoting the hospital? Is it successful in this? Explain.
11. What other goals do you see as relevant for the Center and its operation?

Interview script for Health care professionals:

1. Do you refer patients to the Resource Center for more information?
2. How do you perceive the Resource Center's operation in the context of the hospital?
3. What do you think about the provision of consumer health information in hospitals?
4. What kind of resources do you give your patients to take home?
5. Do your patients generally seek out information about conditions on their own?
6. Do you encounter patients with a lot of knowledge about their conditions? How does this affect your communication with them?
7. Do you see ways the Resource Center can be improved?
8. How does the Center meet the goal of informing the public? Is it successful in this? Explain.

9. How does the Center meet the goal of teaching the public? Is it successful in this? Explain.
10. How does the Center meet the goal of promoting the hospital? Is it successful in this? Explain.
11. What other goals do you see as relevant for the Center and its operation?

Interview with Resource Center user

1. Does the Patient and Family Resource Center meet your information needs? Why or why not?
2. What resources do you use the most often?
3. Do you find the language of the resources hard to understand?
4. What resources would you like to see at the Center?
5. How often do you use the Center?
6. Do you find the extensions of the Center (book carts in the Lobby etc) to be helpful? Why?
7. Would you like to have patient information in the waiting room?
8. Do you think the Center meets your information needs? Why? Why not?
9. What other services offered by the Center do you find helpful?
10. Do you think increasing your knowledge about your condition helps your communication with the doctor?
11. Do you think the Center is successful in teaching patients and their families? Explain.
12. Does the Center help promote the hospital? Explain.

Interview Closing:

It has been a pleasure interviewing you and I really appreciate you taking the time to meet with me. (Summarize interview comments here) Is there anything else you think would be helpful for me to know for my research? I think I have all the information I need, but would it be all right if I contacted you via email with more questions? Thanks again.

Appendix B: IRB Consent Form

University of North Carolina-Chapel Hill
Consent to Participate in a Research Study
Adult Participants
Social Behavioral Form

IRB Study # 08-0158

Consent Form Version Date: 02-27-08

Title of Study: Patient Education and Consumer Health Information: Research on the Patient and Family Resource Center at the UNC-CH Cancer Center

Principal Investigator: Lindsey Ritter

UNC-Chapel Hill Department: Information and Library Science

Faculty Advisor: Claudia Gollop, PhD.

Faculty Advisor email: gollop@ils.unc.edu

Study Contact/ P.I. email: linritt@email.unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, any questions you have about this study at any time.

What is the purpose of this study?

We want to understand how the Patient and Family Resource Center operates in the hospital by gathering information from the perspectives of the Center Administrator, a librarian, Center users and healthcare professionals. We also want to learn about how users find and use consumer health information and how the Center is facilitating this use in the hospital.

How many people will take part in this study?

If you decide to be in this study, you will be one of approximately 8 people in this research study.

How long will your part in this study last?

The interview will take between 45 minutes and one hour. You can choose to stop the

interview at any time.

What will happen if you take part in the study

I will ask you questions about how the Resource Center is used, what resources it offers, how it is promoted in the hospital and your opinions about consumer health information and education. I will take notes about what you say. You do not have to answer any questions that you do not wish to answer, for any reason.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. Your participation is important to help us understand how consumers and healthcare professionals use health information, but you may not benefit personally from being in this research study.

What are the possible risks or discomforts involved from being in this study?

We do not think you will experience any discomfort or risk from the interview.

How will your privacy be protected?

The interview notes will be assigned a code that will be linked to a participant list. This list will be kept under lock and key. Your name and your initials will not be used in the presentation of this research to others, so no one here in your community, or elsewhere, will know what you said. Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for purposes such as quality control or safety. All attempts will be made to insure your identity is not revealed; however, there is the possibility of being identified through deductive disclosure.

Will you receive anything for being in this study?

I am not going to pay you for your information, but your information is very important to us. Your participation is voluntary. As a University or UNC-CH Hospitals employee, a decision not to participate has no effect on your employment or benefits.

Will it cost you anything to be in this study?

There are no costs for being in the study.

What if you are a UNC employee?

Taking part in this research is not a part of your University duties, and refusing will not affect your job. You will not be offered or receive any special job-related consideration if you take part in this research.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions, or concerns, you should contact me by email at linritt@email.unc.edu. You can also contact me or my advisor in the United States at the phone numbers and email addresses listed at the beginning of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Title of Study: Patient Education and Consumer Health Information: Research on the Patient and Family Resource Center at the UNC-CH Cancer Center

Principal Investigator: Lindsey Ritter

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

Signature of Research Participant

Date

Printed Name of Research Participant

Signature of Person Obtaining Consent

Date

Printed Name of Person Obtaining Consent