WHAT DO NEWLY DIAGNOSED PATIENTS HAVE TO SAY REGARDING THEIR PREPARATION AND ONGOING NEEDS DURING THE EXPERIENCE OF CHEMOTHERAPY?

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in
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by
April Palmer
Summer 2009
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ABSTRACT

WHAT DO NEWLY DIAGNOSED PATIENTS HAVE TO SAY REGARDING THEIR PREPARATION AND ONGOING NEEDS DURING THE EXPERIENCE OF CHEMOTHERAPY?

by

April Palmer

Master of Science in Nursing

California State University, Chico

Summer 2009

The purpose of this qualitative study was to understand the lived experience and concerns of patients during cancer chemotherapy. Phenomenological research methodology was used in data analysis. A purposive sample of five participants agreed to one-on-one interviews. The interviews were audio taped and the transcribed data was analyzed for major themes. Data analysis revealed six themes: Fear of the unknown, Importance of hope, Unexpected severity of side effects, Unanticipated/surprising side effects, Lack of knowledge/specific instructions, and Seeking help/resources from others. This study describes in detail the themes identified during data analysis. Findings from this study clearly indicate that the cancer chemotherapy experience continues to
present challenges and patients are struggling with self-care and symptom management. Further research is needed and nursing practice must provide for integration of supportive care, high quality teaching and learning experiences.
CHAPTER I

INTRODUCTION

The diagnosis and treatment for cancer is a very distressing experience for patients. Often, they are quickly bombarded with “cancer information,” from the doctor and nurses, who are following current trends to divulge comprehensive and thorough facts and statistics. Then, family, friends, “friend of a friend,” and neighbors want to share their knowledge and personal experiences (or horror stories, as the case may be.) Of course, with technology, patients also have the Internet to supply them with valid and not-so-valid information about their diagnosis. Often cancer patients do not even have time to acknowledge, absorb or digest the frightening news before they must begin to make treatment decisions about their life. These patients are at high risk for multiple problems and increased anxiety levels. It is imperative that they receive the necessary information that is vital in coping with the effects of chemotherapy treatment.

Background

There has been much research identifying the informational needs of patients and when interventions are designed to educate patients, positive results can occur. A 10-year review of cancer-related patient education overwhelmingly established that cancer patients do desire information and wish their providers to be the primary source (Chelf et al., 2001). However, ongoing surveys consistently report that patients are not satisfied or
felt they did not receive the information they needed to cope with chemotherapy
treatments and side effects. There is little information on educational needs along the
treatment continuum or about patient preferences concerning specific information they
wanted or needed (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004).

Problem Statement

A review of the literature (Audit Commission, 2001; Chelf et al., 2001; Davidson, 2005; Hill, Amir, Muers, Connolly, & Round, 2003; Moumjid et al., 2003; Sarna et al., 2005; Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004; Soothill, Morris, & Thomas, 2003) indicates that patients want and need more information on managing symptoms and emotional consequences during chemotherapy treatments. Gaps in the literature involve the scarcity of data which comes directly from patients. Qualitative studies are needed which provide valuable insight and perspective from persons who are or have “lived” the experience of chemotherapy and its’ side effects. In particular, cancer affects the elderly disproportionately. There is very little research focusing on cancer, the elderly and managing effects of chemotherapy (Heidrich, Egan, Hengudomsub, & Randolph, 2006). Skill of healthcare providers in communicating information must also be considered, along with the patient’s ability to receive information. Psychosocial distress, resulting in increasing anxiety, also interferes with a patients’ ability to concentrate, understand or learn new information. The era of managed care and its financial cost cutting means less time for teaching in general.

The Institute of Medicine’s National Cancer Policy Board cites numerous challenges that continue to hinder the development and delivery of supportive care for
chemotherapy outpatients. Challenges cited include “paucity of clinical data, lack of adequate compensation, and absence of institutional practices” (Miaskowski, Eilers, & Dodd, 2004, p. 3). Supportive care has not kept pace with other advances in cancer management. In fact many areas, including the delivery of information, remain in the “embryonic stages” (p. 3).

Relevance and Importance to Nursing

There is important clinical relevance for the future education of chemotherapy patients. Health policy and clinical practice have placed increasing importance on measuring outcomes of cancer care. The Agency for Healthcare Research and Quality use health-related quality of life (HR-QOL) as one framework for measurement and cite “responsiveness to patient-centered need, preferences, and outcomes is one of the hallmarks of quality healthcare” (Lawrence & Clancy, 2003, p. 709).

The findings of general themes from this study can help to tailor informational sessions and designate when individual intervention is necessary. In addition, it is anticipated that study outcomes may provide information on how patients can utilize better their own coping skills in order to perform self care and management of symptoms and side effects. By learning to meet cancer patients’ needs and wants, healthcare providers may be able to improve patients’ abilities to perform effective self-care behaviors, giving them more confidence, and decreasing the early treatment terminations due to side effects (Williams & Schreier, 2004).
Conceptual Underpinnings

Information-processing theory is the conceptual framework that guides this phenomenological study. Newell and Simon (1972) developed this theory to describe decision-making and how people organize information using knowledge, experience, and cognitive processes to solve problems. Instead of looking at how decisions should be made, this theory uses an open interaction between a problem solver and a task. There are also two assumptions: 1) there are limits to the information that can be stored in short term memory and 2) there are limits to the amount of information that can be concentrated on at one time. These assumptions are critical for the newly diagnosed cancer patient who must process information related to diagnosis, treatment and self-care while under stress. With information gained from this study on personal experiences in dealing with the side effects of chemotherapy, Newell and Simon’s information-processing theory can help to improve healthcare providers’ assistance to patients’ and their ability to manage symptoms. Past learning experiences and life experiences as related to information-processing and self-care needs can be connected. This theory is useful in linking the problem-solver (patient) to the problem-situation (cancer chemotherapy) and identifying individualized ways of coping.

A second theoretical framework underlying this study is the Self-Regulation Model (SRM). The SRM provides a theory in understanding how physical symptoms are interpreted and how they provide feedback about aspects of one’s illness, such as its consequences and progression. Responses to health threats cause behavioral and emotional responses, such as anxiety and depression, and can vary depending on the experience of new symptoms. These symptoms may be perceived as new threats to their
health state. Individuals use pre-existing knowledge to make sense of these perceived threats and responses are adjustable and vary (Thune-Boyle, Myers, & Newman, 2006). It is important to understand how newly diagnosed cancer patients are managing their symptom experience. Healthcare providers can use the SRM model to personalize symptom management and decrease individual’s perceived threats. The current study can look at how patients’ behavioral and emotional responses affect their self-care capability either positively or negatively. Successful self-regulation and decreased anxiety helps patients adapt and cope with chemotherapy treatments (Keller, 2006).

**Purpose/Research Question**

The purpose of this study is to understand the concerns and unmet self-care needs from the patient’s perspective. The following qualitative research question will be used to explore this issue: *What do newly diagnosed patients have to say regarding their preparation and ongoing needs during the experience of chemotherapy?*

Qualitative studies are a good way to gain information that can help guide nursing practice. By understanding the patient’s perspective or lived experience, providers can tailor teaching to consistently match the needs and coping skills of their patients. Patients deserve to have their healthcare providers give information that they want and in a way most beneficial. In addition their concerns should be elicited and discussed at every junction of their treatment continuum. The growing number of articles in the literature on health-related quality of life and the increase in research on patient-centered outcomes attest to the importance of patient’s perspectives.
Definitions of Terms

Cancer

“Abnormal cells which grow out of control” (American Cancer Society, 2008a).

Chemotherapy

“The systemic administration of anticancer chemicals as treatment for cancers that are known or suspected to be disseminated in the body” (Copstead & Banasek, 2005, p. 171).

Newly Diagnosed

These patients have a new primary cancer, have been diagnosed within the last 6-8 weeks, and have no previous history of any cancer.

Qualitative Research

“Research to help in the understanding of social phenomena in a natural rather than an experimental setting with an emphasis on the meanings, experiences, attitudes, and views of the participants” (Meadows, 2003, p. 464).

Phenomenology

“Research method which is used to fully describe a person’s lived experience of an event or experience” (Mapp, 2008, p. 308).

Qualifications

The researcher qualifications include 16 years in medical surgical nursing, with 8 years devoted to oncology. The researcher is an Oncology Certified Nurse (OCN), a member of the Oncology Nursing Society, Radiation Therapy Oncology Group, and
enrolled in a Master’s of nursing program at Chico State University. She is currently employed at a cancer center specializing in chemotherapy and radiation therapy. Working with adult cancer patients primarily, the medical oncology group receives approximately 275 office visits and an average of 19 new consultations monthly (NorthBay Medical Oncology Audit Report, 2007).

Summary

Providing patient-centered care requires enhanced understanding of what patients experience while receiving chemotherapy treatments. Specifically, qualitative information is needed on patients’ views regarding unmet needs while under treatment. In-depth analysis of past and present literature on patient and symptom management of chemotherapy side effects can contribute to nursing knowledge. Chapter II will review the literature on chemotherapy education, symptom management, and quality of life. Many studies have looked at what topics to cover and ways to deliver the information. Missing are qualitative studies that provide patients’ perspective on the preparation and management of chemotherapy treatment and living with the side effects.
CHAPTER II

LITERATURE REVIEW

Chapter II will examine literature involving patients’ needs and wishes regarding chemotherapy treatment and teaching surrounding the management of physiological and psychological side effects. The American Cancer Society [ACS] (2007) estimates over one million new cases of cancer were diagnosed in 2008 with chemotherapy prescribed for many of those. Chemotherapy is a cytotoxic systemic treatment used for many malignant and some nonmalignant diseases. Depending on treatment regimen, side effects may include nausea, vomiting, loss of appetite, sore mouth, hair loss, skin rashes, tingling, numbness, immunosuppression, weight gain, cessation of menstruation, neuropsychiatric effects, anxiety, and depression (ACS, 2008b).

With the trend to move care from inpatient hospitals to outpatient clinics, almost all chemotherapy is done on an outpatient basis (Allwood et al., 2002; Taylor & Birch, 2004). Patients are now increasingly performing self-care of most symptoms and side effects. In addition to symptomatic physical management of toxic side effects, symptoms are also reminders of action needed.

A well-respected author and researcher of symptom management, Marilyn Dodd of the University of California, San Francisco (UCSF), has investigated nursing interventions to facilitate self-care practices of patients with cancer. These interventions
decreased treatment morbidity and have contributed towards the development of the Symptom Management Model. When patients are not properly prepared for the experience of chemotherapy their quality of life decreases significantly due to poor symptom management (Dodd, 2008). Findings from the current study can illuminate patients’ needs within this holistic model, linking symptoms, self-care and management.

Classic Research

Two important decade-long research systematic reviews looked at studies on the topic Cancer-Related Patient Education. Common themes to both were the correlation between the levels of satisfaction with information received and ability to cope. The first review was conducted by a research committee from the well-respected National Cancer Institute (NCI), (Chelf et al., 2001). Primary objectives were to contribute to the body of knowledge and to promote the use of evidence-based education practices at NCI-designated centers. The NCI-Cancer Patient Education Network committee was made up of leaders in cancer patient education from various NCI-designated cancer centers and they performed computerized literature searches for the period 1989 to 1999. The databases they searched were Medline, CINAHL, HealthStar, ERIC, CancerLit, and PubMed. They did not limit their search to oncology education but looked only at English-language articles. Search terms included: Information needs, health knowledge, literacy, teaching methods, oncology, computer education, patient education, evaluation, and research.

A total of 436 abstracts and 176 articles were reviewed and separated, once broad topic areas were defined. These topic areas were the following: Information
needs/learning preferences, utilization of print media, literacy/readability, computer-assisted learning (telephone/audio/video), treatment decision making, treatment education, pain, and fatigue. All literature was read by two different committee members to help assure reliability and validity during research.

Key points from this systematic review of research studies confirmed that patients need and want information from their healthcare providers; that positive educational experiences provide positive outcomes; educational literature’s usefulness has not been studied; internet usefulness has not been studied; and that there is a continuing need for improved patient education (Chelf et al., 2001).

A second important comprehensive literature review (Audit Commission, 2001) was done in the United Kingdom (UK) and it paralleled that of the NCI’s. The UK government, long concerned with the importance of patient information, listed this as a proposed reform for the National Health Service. The commission highlighted a serious lack of communication between hospitals and patients. These factors prompted researchers to conduct a review of the literature from 1990 to 1998. This review, however, limited literature to only those directly related to information giving and the patient who had been recently diagnosed with cancer. Key concepts included: Difficulty identifying influencing factors (age, gender); difficulty seen in delivery of information (literacy levels); and nurses found lacking in meeting needs (skill, time). There can be limitations with these types of retrospective reviews. One limitation, which is an inherent problem with electronic databases, is that if articles are improperly indexed they would not be found during a search. A second limitation is that studies which are small in
sample size and specific to breast cancer can affect the ability for generalizability of findings to the population as a whole.

Current Research

Recent studies (Davidson, 2005; Soothill, Morris, & Thomas, 2003) continue to identify deficits in the area of patient teaching and informational needs met. This occurs across different cultures and varying diagnoses. Patient satisfaction is dependent on information provided, clarification of disease/treatments, and the ability to talk about emotional issues surrounding diagnosis and treatment. High reports of dissatisfaction are especially found in these areas and assessment/management of side effects.

A study using focus groups (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004) in a regional rural academic medical center recruited 51 participants and an additional 14 spouses. In two-hour sessions, which were audiotaped and led by trained facilitators, participants discussed the nature of their symptom experience and how inadequately they were prepared for treatment-related side effects. Findings indicated that patients did want information and sought information from a variety of sources. The authors cited varying obstacles to obtaining information about dealing with chemotherapy side effects such as access to providers, communication difficulties with providers, informational overload, and problems with retention.

Lung cancer is the leading cause of death worldwide (World Health Organization [WHO], 2006). A study of 80 newly diagnosed lung cancer patients was conducted to assess if their concerns were being met. Participants were asked 17 specific questions using a scale from 1 (no worry) to 5 (extremely worried). Of the 18 concerns
categorized, the three highest worries were about the illness itself, the illness and the future, and their family. Findings indicated that patients felt that less than half of their concerns (43%) had been considered by the healthcare team. It should be noted that concerns were rated as adequately discussed if more than 50% of the patients who were worried about an item reported that this was discussed by the healthcare team.

Particularly insightful was the obvious lack of emotional and psychosocial support from healthcare providers, yet lung cancer patients reported these symptoms were more worrying to them than their physical symptoms (Hill, Amir, Muers, Connolly, & Round, 2003).

Information guiding assessment and interventions to support quality of life is also limited. Lung cancer and quality of life were considered in a large cross-sectional survey of 217 women (Sarna et al., 2005). Most participants reported numerous serious disruptions in their psychological and social well-being and feeling ill equipped to deal with the challenge of chemotherapy treatment and its' side effects.

Informational handouts and booklets are a common way to present cancer information, but can be too general or incomplete. A focus group (Moumjid et al., 2003) of breast cancer patients and healthy volunteers were given information booklets to critique. Results found common themes emerging, such as missing information or lack of detail. For example, missing information included common occurrences such as the use of antibiotics, emergency hospitalizations for adverse/toxic effects from chemotherapy, weekly dressing changes, and clothing damage from ink markings. Several felt it would be helpful to know this information upfront so as to make arrangements for home visits or childcare or dressing appropriately. Even though the material was written by
professionals with the information considered high quality, many changes were suggested by the focus group to make it more patient-friendly, practical and useful. Discussion from the focus group also raised awareness of the timing of handouts and questioning the need for healthcare providers to explain treatment before test results are conclusive.

Implications

The importance of the patient’s perspective is clear and widely recognized. The rising trend for chemotherapy given in outpatient settings and in patient homes has significant implications. Detailed information and education will be required for these patients to manage problems when home alone and have limited contact with chemotherapy specialists. Teaching self-care behaviors increases patient satisfaction, control, comfort, and overall quality of life (Williams & Schreier, 2004). Chapter III will focus on research methodology and a description of the sample, including data collection and reliability. Theoretical and ethical considerations will also be discussed.
CHAPTER III

METHODS

Classic and current literature demonstrated the continuing pattern of problems in the area of patients’ ability to manage chemotherapy treatments and the resulting side effects. Patients want and need more information (Chelf et al., 2001; Audit Commission, 2001; Davidson, 2005; Soothill, Morris, & Thomas, 2003) and healthcare providers are deficient in this area (Moumjid et al., 2003; Sarna et al., 2005; Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004; Hill, Amir, Muers, Connolly, & Round, 2003). New research, especially qualitative, rich in patient experiences, will be explored in this chapter.

Research Methodology

The qualitative research method chosen was phenomenology, which is used to search for the essence or real meaning of a lived experience. First-hand descriptions of experiences can then be transcribed and analyzed for themes and meanings which allows the experience to be understood and provides insights. Phenomenological research “stresses that only those that have experienced phenomena can communicate them to the outside world” (Mapp, 2008).

For the qualitative aspect, data analysis is used to define concepts and understand internal composition. Data must be carefully categorized and only sections
that convey the most important information are selected. Theorizing or searching for explicit or implicit explanations, exploration and/or finding of associations can occur (Meadows, 2003). Participants will be asked general questions about the experience of chemotherapy and if there were areas in which they felt unprepared or were surprised about. Participants will also be asked to share any recommendations about educational needs pretreatment.

Sample

The study setting was a cancer center serving a moderately-sized county in Northern California. According to the U.S. Census Bureau *State and Government Quick Facts* (2005), this county has a population of approximately 411,593. Of those, 64% are white, 20% Hispanic, and 15% were Black. Median income is $56,500 in this urban area. The cancer center is located in a freestanding clinic adjacent to the main hospital and the number of cancer patients utilizing services in 2005 was approximately 500. Of those, 134 were breast cancer, 89 were lung cancer and 50 were prostate cancer patients (NorthBay Cancer Center, 2005).

A purposive sampling of five study participants was chosen by the principal investigator and cancer center clinical coordinator. Participants were reflective of the general county population characteristics and met both inclusion and exclusion criteria. Inclusion criteria were a) newly diagnosed patients who have completed the first cycle of chemotherapy, b) only one primary cancer diagnosis, and c) have never received chemotherapy treatment previously. Exclusion criteria were a) communication barriers and b) cognitive deficits. Completion of the first cycle of chemotherapy was chosen so
that participants would have experienced treatment and/or possible side effects, but would be beyond the initial shock of diagnosis.

Participants’ ages ranged from 30-66 years old, with 3 being female, 2 male. There were 3 Caucasians and 2 Blacks. All participants reported having a 12th grade education. Participants had diagnoses of anal, breast, prostate, bladder, and rectal cancer.

Ethical Considerations

Nursing research is critical to produce and refine knowledge related to sound nursing practice. Ethical conduct while performing nursing research is also critical and an awareness of study participants’ human rights should be at the forefront of all decisions and phases of any study. Having rights is necessary for the self-respect, dignity, and health of an individual (Sasson & Nelson, 1971). Specific human rights which require protection during studies include the right to self-determination, the right to privacy, and the right to autonomy and confidentiality. Because adults have the freedom to conduct their lives as they wish, the participant’s right to self-determination was protected by providing a verbal description of the study to each potential participant during initial meeting. Participants were informed of any chart review or data collected. Reinforced was the voluntary nature of participation.

The individual’s right to privacy, autonomy, and confidentiality was protected and safeguarded. With assigned identification numbers, complete anonymity occurred with all demographic data, response data and study reports. Participants were given a written informed consent to read and sign (see Appendix B). There was the possibility of emotional risk in reliving any unpleasant experiences and mental health referral was
available but not necessary. There were no direct benefits to participants with this study. It was explained that anticipated information gained from this study may eventually help future patients in meeting educational needs pretreatment.

Data Collection

Interviews began shortly after receiving hospital IRB approval. A five-question demographic questionnaire designating name/assigned identification number, age, gender, race, and educational level was initiated, coded and entered into a database (Appendix A). Written informed consents were obtained for participation and audio taping for all participants (Appendix B).

Interviews were conducted in private conference rooms at the cancer center and scheduled directly after follow-up appointments with their physician. All interviews were audio taped to capture participant’s perception and average length was approximately 42 minutes. Unstructured one-on-one interviews were initiated with “Tell me about your experiences with cancer chemotherapy.” Participants were also asked to share what memories stand out most clearly regarding their preparation for cancer chemotherapy and how well or not well ongoing needs were met. At conclusion, participants were asked if they had any recommendations for future patients.

Audio tapes were immediately transcribed verbatim. The investigator then began data immersion to truly discover participant’s meanings within the experience of living with cancer chemotherapy. Transcripts were read and reread in their entirety. Data were continually analyzed and cross-referenced to look for similarities, differences, and identification of patterns or themes. Themes were coded by number and marginally
marked on each transcript. Significant statements were extracted and linked to formulated meanings.

Principles of Colazzi (1978) method of analysis were utilized to maintain trustworthiness of the data, including investigator rephrasing participant’s statements during the interview to defend against misinterpretation. Participants were also re-contacted as necessary for verification that interpretations were correct. All participants verified that transcriptions were accurate and depicted their true life experiences with cancer chemotherapy.

Rigor

Components to assure trustworthiness of data included credibility, auditability, confirmability, and transferability (Guba & Lincoln, 1994). To ensure credibility, all participants reviewed final readings for truth in the findings or to verify that descriptions were authentic and representative of their experience. Auditability will enable readers to understand the rationale and follow the raw data through an audit trail or decision path through the various steps of analysis to the interpretation of findings. Data review was completed by a second reader to avoid researcher bias and ensure confirmability. Transferability refers to the ability to recognize the common realities and provide details so that the implications of important findings have significance for others in similar situations. To help demonstrate rigor, a data display was used to build a picture of the range and nature of the phenomena. Significant statement, meanings, and themes can be mapped and associations plotted in a systemic way (Meadows, 2003). Phenomenological research can help to give insight and meaning to the lived
chemotherapy experience. This knowledge and insights gained can help to guide and improve nursing practice.
CHAPTER IV

DATA ANALYSIS

Data collected gave broad, deep and poignant descriptions of the actual lived experience of receiving chemotherapy treatments and living with its side effects. Data analysis revealed six themes that were common to all or most participants without regard to their age or sex. Participants reflected these themes but in varying degrees. Themes included: 1) Fear of the unknown; 2) Importance of hope; 3) Unexpected severity of side effects; 4) Unanticipated or surprising side effects; 5) Lack of Knowledge/specific instructions; and 6) Seeking help/resources from others.

Table 1 depicts an example of a significant statement linked to a theme and corresponding meaning. A detailed discussion follows describing each theme.

Table 1

Selected Example of Significant Statement and Corresponding Meaning

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<th>Significant Statement</th>
<th>Theme</th>
<th>Meaning</th>
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<tr>
<td>…it’s the fear of the unknown, most know cancer is a one-way street</td>
<td>1 - Fear of the unknown.</td>
<td>Fear of death.</td>
</tr>
<tr>
<td>….you’re laying there and thinking, now what is this going to do to my body</td>
<td></td>
<td></td>
</tr>
<tr>
<td>…in the back of your mind, you always think it is going to come back</td>
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Theme 1: Fear of the Unknown

All participants freely spoke about fears surrounding their cancer treatment. Most expressed feelings of fear regarding the unknown. All were scared, one even terrified, when first finding out that chemotherapy would be recommended. Not knowing exactly what to expect but having heard many ghastly stories about chemo, they lived in dread. One participant did not want to panic but wondered if she would be sickly looking, bald-headed and weak all the time. “You know, you have so many questions and you don’t know because everybody is different, I just didn’t want to be surprised.”

Several spoke specifically about fear of an unknown future, “You know, with cancer it can go away but you never know, it could come back……..can be years down the road, but you never know……..in the back of your mind, you always think it is going to come back.” Because of a family history, one participant told her surgeon that she had waited all her life to be told she had cancer, she only feared when the day would finally come if she would be ready. Several participants talked about being okay with the chemotherapy and all that it entails, however, knowing that cancer is a “one-way street” brings about a terrible fear of the future and what it might mean to them in terms of possible suffering. They spoke about chemo being able to slow the disease down, but in reality the unknown future is “all you can think about.”

Theme 2: Importance of Hope

The importance of hope was a significant theme that most participants spoke about during the interviews. During difficult periods, family, friends and healthcare providers with positive attitudes that spoke about hope was of immense value. When
some expressed feelings like “giving up” or “not going to make it” words, offering hope from others, encouraged participants beyond belief. Reminders that side effects were temporary or that hair would grow back, possibly even better than before, or energy levels will return, all offered participants hope when they were unable to feel hopeful themselves.

…when you’re in the chair getting chemo you know your future is jeopardized….your gums are bleeding, your hair is balding out, you look like a stick figure…but the best thing was when the ladies (nurses) in here had a relatively jovial attitude and would talk about what we planned to do tomorrow or the next day or the next day when we felt better—not if we felt better—but when we felt better…..I think the worst thing about this disease and treatment is when people keep their mind on it…you lose all hope…when really you gotta live….(Participant #2)

Almost all participants talked about having hopeful, positive attitudes, even during the worst times. One man told himself “What are you gonna do? Live with the sadness of dying or just live?” He went on to speak of taking himself to another place when he felt himself losing hope. When he focused on the chemotherapy he felt “totally rotten, like I shouldn’t be here, my life is compromised and negative, negative, negative.” By going to another place mentally “the fun and games” or times of hunting and fishing, his attitude shifted. He would begin to regain hope and again enjoyed living, his family, and planning his after treatment cruise.

Several mentioned that their faith, trust in God, and praying gave them hope and help “in climbing out of the doldrums of cancer.” One participant talked about receiving hope from her mentor and encouraging coach - an older sister. As a breast cancer survivor, who received the harshest and strongest chemo possible, with a near-death pneumonia episode, she is now, nine years later, doing wonderfully.
Theme 3: Unexpected Severity of Side Effects

Participants discussed being aware of specific side effects, but unaware of the degree or to the extent with which they would experience these. All mentioned feeling fatigued or tired, but were ignorant of the toll it would take on their well-being. Rather than simply feeling tired, descriptions of “drained,” “very weak,” “low on everything,” “no energy at all,” “no strength,” and “spent most of the time in bed” were used to try and capture the true feelings of what one feels like with cancer chemotherapy fatigue. One participant mentioned the “gradual buildup” of fatigue and that it accumulated, being much more intense towards the end of treatment. Although he was seen weekly, very little was discussed in terms of “your fatigue, your energy level, and that type of thing.” Another participant mentioned being unaware of the amount of time it would take to regain her energy levels, hoping they would come back soon.

Several participants recalled the possibility of diarrhea but did not realize the amounts or frequency. One man spoke of frustration when, after an initial heavy bout of diarrhea, he called his healthcare provider to discuss the instructions on the box of antidiarrheal medication. It took three days for a return call.

The extent of the loss of taste and how that affects one’s ability to eat was reported by several as being worse than they expected. All recalled knowing that taste buds would be altered but as one participant said, “taste is a real big thing, when nothing tastes good, you don’t eat.” All experienced weight loss related to nausea, diarrhea and/or impaired taste.
For the three female participants, hair loss, though not a surprise was particularly difficult to live with. Feeling “ugly” and concern over hair returning and how long it would take, what color and texture it would be, all caused anxiety. One participant spoke of the distress of watching her hair thin and fall out, sometimes by the handful and often during the night so that she would wake to find fistfuls of hair on her pillow. She also shared one time when “my hair locked on me” and it felt like wool, matted and stuck. Panicking, she fled to her hairdresser who told her that chemo kills hair and is especially damaging to straightened or bleached hair.

Theme 4: Unanticipated or Surprising Side Effects

Almost all participants reported at least one side effect that they had not anticipated or were surprised about. Of the ones reporting, none remembered any discussion from their healthcare providers. Several felt that if they had been prepared, it would have been easier to tolerate. In regards to fatigue, one participant felt if he had known earlier he would have taken more naps during the day which might have increased his energy level or at least not felt so drained. Another participant was not aware he would feel tired all the time and at first mowed the front and back yard lawn as he was accustomed to doing. Later on he realized that he needed to space his chores and rest in between.

All participants strongly emphasized that surprises were negative and wished to be informed prior to treatment of any possible consequences. One female participant mentioned feeling great during the first five days of chemo, even feeling like “Wonder Woman” and was completely blindsided on day six when the full effects of the chemo hit
and she became violently sick, nauseated, and weak. The surprise was in the delay of the effects and the force with which they came. Also unexpected was when a participant was told that lip ulcers would not occur with her type of chemo. The surprise came during the second week when she did in fact have “her lips swell and bust open.” Her doctor related that this was very unusual, unfortunately for her. At times, secondary diagnoses can result and are labeled chemo-induced. Two participants had unanticipated events: diabetes and chronic constipation.

Several of the participants spoke of unanticipated emotional consequences. One woman in her early 30s, with 3 young children, felt she was not at all prepared and felt overwhelmed. She was surprised that she was often teary, spent all day in bed, and would rarely leave the house. Another participant expressed sadness about not being the same person as before cancer chemotherapy and having to live life differently afterward.

Theme 5: Lack of Knowledge/ Specific Instructions

All but one of the participants spoke of standard or generic handouts given to them that listed possible side effects. One participant did not receive any written literature. The lists were described as basic but side effects vary depending on type of cancer, treatment, single treatment versus combined treatment, and, of course, individual tolerance. “They give you a whole list of side effects and you don’t know which one you’re looking for or which one you’re going to experience. Okay, so you’re looking, is that part of the chemo? Did the chemo do this?” All participants wished for specific instructions which discussed only their cancers and their specific chemotherapies. Many of the participants recalled having side effects not on the list at all. When treatments were
combined, information was still only given for one aspect with that list of possible side effects.

Two of the participants were sent home with their chemotherapy infusing via fanny packs with portable batteries. Each experienced apprehension of the equipment and lack of knowledge regarding handling problems. One asked for a booklet and was told there is no booklet.

I went home with the chemo scared to death, thought it was going to bust open because I’m sleeping in the bed with it. Uh, I had to try and bathe with the pack so I had to cover the pack in plastic and then bathe. Then when I got dressed I had to put it in the sleeve, that was a hassle. I was thinking in my mind its only 5 days, only 5 days. So as long as I thought like that it was okay. (Participant #3)

Both had experiences of the fanny pack machines beeping in the middle of the night which were cases of the battery running low. One of the participants awoke startled and worried about a leak or possible bubble in the line and was relieved to see it was only the battery light flashing. She was so nervous about handling the machine that she called the 24-hour hotline number imprinted on the bag and a pharmacist talked her through changing the battery. It was about 1 or 2 a.m. and the whole incident left her exhausted, physically and mentally.

Theme 6: Seeking Help/Resources from Others

All participants described seeking information from sources other than their healthcare providers. Whether this was a result of personal preference, limited access to their physicians or not wanting to bother anyone is unknown. Reported sources included literature, periodicals, television, internet, and family/friends with a chemotherapy history. One man stopped searching on the internet when he realized that not all
information was necessarily valid. He said, “you know the old fella at 65 still has a library card” and began his own research on his cancer chemotherapy. Another man searched for support groups but found that his type of cancer did not have any, unlike for breast and prostate patients.

Most participants gleaned information from family members who had been through chemotherapy. One woman’s sister lived out of state but was available by phone to answer questions, sometimes daily. Another spoke of having a mother, father and 2 sisters who all had cancer. They were a wealth of information about chemotherapy treatments. She also talked about receiving misinformation of which she would eventually clear with her chemo nurses.
CHAPTER V

DISCUSSION

The chemotherapy experience continues to present challenges for those who are receiving it. Findings from this research confirm major issues presented in the literature review which highlight the need for continued diligence in supporting patients through this experience. Participants’ views clearly demonstrated the need for improved education and supportive care, not only pretreatment, but continuously throughout the treatment.

Data from this research and past research (Hill, Amir, Muers, Connolly, & Round, 2003; Sarna et al., 2005) clearly illustrated that quality of life decreases with poor symptom management. Dodd’s UCSF Symptom Management Model (2008) links the cyclical symptom experience: Perception of symptoms-Evaluation of symptoms-Response to symptoms. Participants all reported varying levels of dysfunction in managing symptoms, especially when they were either unanticipated or severe.

The SRM or Self-Regulation-Model explains how participants’ symptoms are interpreted and providing feedback to them. Several talked about their illness in terms of consequences and progression, feeling the “threat” of their chemotherapy experience and having anxiousness as a result. Past learning and life experiences related information-processing to self-care needs. In positive cases, one participant explained “I educated myself on it; I was prepared or knew what chemotherapy was and what the chemotherapy
does to your body.” “I’ve had side effects that I’ve beat back, I go and do something to take my mind off it.” Participants’ views on symptom management gave clues as to the success or lack of success of their information-processing or SRM abilities. When past learning/life experiences were lacking, it was difficult for patients to positively regulate self-care in an acute phase.

Limitations

The major limitation of this study was that it only represented analysis of a small sample. Results may not be generalizable but the fact that findings do support available literature suggests that current practice is not effective. Alternative strategies should be explored and larger studies considered determining the degree to which the views of these five participants are representative of cancer chemotherapy patients. A second limitation was that not all cancer diagnoses or chemotherapies were assessed. A more comprehensive study might offer further insights.

Implications

Cancer chemotherapy is constantly changing and has shifted from hospital-based care to community-based care (Allwood et al., 2002; Taylor & Birch, 2004). Findings from this study and past research indicate that patients are struggling in self-care practices at home and need assistance. Nurses can use SRM theory to assist patients with choosing only the most relevant information necessary in coping with cancer chemotherapy. This theory explains that responses are based on functional versus emotional. SRM theory helps nurses to redirect emotional responses to a more functional or objective response, which allows patients more control and improvement in coping.
All participants were asked to share any recommendations about pretreatment teaching needs. Common answers were side effect and treatment(s) specific written information, increased access to providers (after-hours), positive/hopeful attitudes from providers, warnings of possible surprises, and to have emotional aspects addressed. These issues speak to quality of life and the struggles many are having. The challenge is for healthcare providers to assess and then provide interventions that address these needs for those undergoing cancer chemotherapy.

Data suggest that relationships between patients and providers need to be established and then nurtured. Providers must be available, receptive and responsive. Outpatients in charge of their self-care at home need more of a mentor and coach, someone they can trust and feel comfortable to go to with questions. Webster’s Online Dictionary (2009) describes a mentor as a “trusted counselor or guide.” Mentors can provide assistance with problem-solving and much-needed support which gives patients the confidence and ability to perform effective self-care behaviors.

Unfamiliarity with equipment and possible malfunctions was verbalized as causing great anxiety and distress. Critical is having a plan outlined beforehand on what to do. Although machine malfunction is an uncommon event, the stress surrounding them can be greatly reduced with appropriate education.

Psychosocial and emotional challenges were important themes in this research that illuminates the continual need for counseling in these areas. Fears and angst expressed by participants revealed the magnitude of the problem and an area that nursing must be more sensitive to whenever opportunities and contacts exist. Clear is the need for
nurses to facilitate more health/stress management, self-coping skills and supportive group psychotherapy.

Recommendations

An increased understanding of the cancer chemotherapy experience can help healthcare providers in assisting future patients. Providing for integration of supportive care, high quality teaching and learning experiences from pretreatment through posttreatment is essential for newly diagnosed cancer patients embarking on chemotherapy treatments.

Data from this research highlights the need for teaching that is specific to the type of cancer chemotherapy. Standardized information or lists routinely given as handouts are not only ineffective, but in some cases caused increased anxiety or stress. One possible strategy concerns the existing teaching approach which is founded on hospital-based care. Nurses may need training in how to prepare patients for cancer chemotherapy within their own home environment rather than the hospital environment. Recommended would be classes involving hands-on and actual walk-through of any or all possible scenarios, including machine malfunctions.

Data also clearly demonstrated that patients are struggling with their own coping skills and need emotional support and counseling. An important strategy would be increased availability of nurses to patients during nontraditional clinic times. Questions often arise at times after clinic or physician visits. Opportunities to call RNs or nurse practitioners after hours would provide support. Communication is critical to relieve anxiety and stress is reduced when patients feel supported by compassionate nurses who
understand their concerns. Recommended Internet sites and facilitation of on-going support groups also would bolster patients’ confidence.

Future research ascertaining symptom management and levels of coping skills would be beneficial. Also, additional research examining long term effects from coping with cancer chemotherapy. Specific research targeting the elderly, many who have comorbidities, is also vital. With the population increasing over the period 2000 to 2050, the number and percentage of Americans over the age of 65 is expected to double. Since cancer incidence increases with age, it is anticipated that there will be a surge of elderly cancer patients requiring treatments and nursing care. The elderly account for 60% of newly diagnosed malignancies (Berger et al., 2006).

The incorporation of on-going supportive care within the patient-client relationship is nowhere more important than in the realm of oncology nursing care. Every point of contact is an opportunity to teach and oncology nurses must strive to improve patient management which will optimize patient outcomes. Alternative and novel approaches by oncology nurses can make a difference in the quality of life for those who must endure cancer chemotherapy. One participant verbalized his wishes regarding teaching: “people that are on these drugs should be educated to a future and not to a disease.”

Nursing interventions need to directly address specific situational concerns including giving information about disease and treatments that will help with self-coping behaviors. Interventions should be directed at offering control of the situation, with exploration of specific concerns and alternatives that ease the burden of illness and treatments on a day-to-day basis. Most importantly, intervention is necessary for the
overall impact of illness and treatments and how those affect individuals’ identity and purpose in life.

The aim of this study was to improve nursing interventions in the future by better understanding the experience and concerns of patients who have been through cancer chemotherapy. The challenge of providing holistic care is in identifying individual needs early to enable appropriate treatments to be offered and to ensure that relevant support services are put in place. Eliciting patients’ concerns and viewpoints is essential and although all concerns cannot be resolved there is potential therapeutic value in facilitating the expression of those concerns.
REFERENCES


APPENDIX A
DEMOGRAPHIC INFORMATION

1. NAME/ASSIGNED IDENTIFICATION:_______________________________

2. AGE: _________

3. SEX: _________

4. CIRCLE THE LETTERS THAT BEST DESCRIBE YOUR ETHNIC GROUP:
   a. American Indian
e. Latino/a
   b. Asian Americanf. Mixed Ethnic background
c. Black/African-Americang. Pacific Islander
d. Caucasian/Whiteh. Other_________________

5. CIRCLE THE HIGHEST GRADE OR YEAR YOU COMPLETED:
IN REGULAR SCHOOL, VOCATIONAL SCHOOL, COLLEGE,
OR GRADUATE PROFESSIONAL TRAINING:

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<th>High School</th>
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INFORMED CONSENT TO PARTICIPATE IN RESEARCH

CHEMOTHERAPY EXPERIENCE

Principal investigator: April Palmer, RN, BSN, MSN(c), OCN
Co-investigator: Janelle Gardner, RNC, PhD
Facility Name: NorthBay Cancer Center
Address: 1860 Pennsylvania Avenue
Phone: 707-646-4040

Date: 3/20/09
File #: NH 09-03
Rec. Secty.: B. Rainier

This is a research study which examines the patients’ perspective or viewpoint about chemotherapy experience. Please take time to make your decision about participation.

Why have I been asked to take part in this research study, and who is conducting it?

You have been invited to take part in this research study because you have been diagnosed with a primary cancer and will have just completed your first cycle of chemotherapy. This study is being conducted by April Palmer, RN, BSN, MSN(c), OCN, as part of thesis research in conjunction with Chico State University.

Why is this research study being done?

This study is being done to better understand the experience of newly diagnosed cancer patients receiving chemotherapy treatments and to gain information that may help guide nursing practice.

How many people will take part in the study?

About 4-6 participants.

What is involved in the study?

After completion of your first cycle of chemotherapy you will be asked about your coping experience while receiving chemotherapy. This interview should take approximately one hour.

How long will I be in the study?

One interview session with possible follow-up.

What are the risks of the study?

There may be the risk of emotional discomfort and you are free to decline to answer any questions you do not wish to answer. If that should occur participants will be assisted in referral for mental health assistance.
Are there benefits to taking part in this study

There are no direct benefits to you for participating in this study. However, it is anticipated that the information gained from this study may eventually help future patients in meeting educational needs pretreatment.

What are the costs?

There are no costs involved in taking part in this study and there is no compensation. You are not being asked to waive any legal rights.

Do I have to be a part of the study?

You may choose to either take part or not to take part in this research study.

If you have any questions about the study, you will have a chance to talk to one of the study staff. Do not sign this form unless you have had a chance to ask questions and have received satisfactory answers. You may also wish to discuss this matter with a relative, a friend, or your regular doctor.

What are my rights as a study participant?

Even after you agree to take part in this study, you may withdraw at any time. Before withdrawing, you should notify one of the people involved with this research. There will be no penalty to you.

Your decision will not affect your routine medical treatment, your relationship with those treating you, or your relationship with this institution. If you withdraw from the study, you will still be offered all available care that suits your needs and medical condition.

Who can I call if I have questions or problems?

If you have any further questions about the study or about being a participant, you may contact the principal investigator, April Palmer, by email at palmerapril@sbcglobal.net or you may contact Diane Smith at Chico State IRB at 530-898-4766.

If you have any questions regarding the way in which this study is being conducted, or your rights as a research subject, contact the NorthBay Healthcare Institutional Review Board at (707) 624-7001.

How will information about me be kept private?

Study records will be kept confidential. No personal identification will be recorded.
By signing this statement, I agree to the release of my Protected Health Information (PHI) to the above listed agencies for the period of time specified (refer to Section: How long will I be in the study?). However, I also understand that I may revoke this authorization to release my PHI, in writing, at any time.

________________________
Participant's Name

________________________
Participant's Signature Date

STATEMENT FOR THE PARTICIPANT

By signing this form, you are showing that you have read this Informed Consent to Participate in Research or it has been read to you. Please do not sign this form unless you understand what is in this form, including the risks described, and all your questions have been answered satisfactorily. Remember that you may withdraw your agreement to be in this study at any time. By signing this form, you are showing that you have freely and voluntarily agreed to the requirements of the study and that you want to take part in this study. You will receive copies of this form and the Experimental Subject's Bill of Rights. All oral and written information and discussion about this study has been provided in English or in another language in which you are fluent.

________________________
Participant's Name

________________________
Participant's Signature Date

________________________
Witness' Name

________________________
Witness' Signature Date

STATEMENT OF THE INVESTIGATOR

This patient has been evaluated for participation in this clinical trial. The risks, benefits and alternative treatment were explained to the patient. The patient agrees to participate in this protocol.

________________________
Investigator's Signature

________________________
Date
EXPERIMENTAL SUBJECT'S BILL OF RIGHTS

The rights below are the rights of every person who is asked to be in a research study. As an experimental subject I have the following rights:

1. To be told what the study is trying to find out.

2. To be told what will happen to me and whether any of the procedures, drugs or devices are different from what would be used in standard practice.

3. To be told about the frequent and/or important risks, side effects, or discomforts of the things that will happen to me for research purposes.

4. To be told if I can expect any benefit from participating, and, if so, what the benefit might be.

5. To be told of the other choices I have and how they may be better or worse than being in the study.

6. To be told what sort of medical treatment is available if any complications arise.

7. To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study.

8. To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study.

9. To receive a copy of this form and the signed and dated consent form.

10. To be free of pressure when considering whether I wish to agree to be in the study.

I have carefully read the information contained in the above "Experimental Subject's Bill of Rights" and I understand fully my rights as a potential subject in a medical experiment involving people as subjects. If I have other questions I should ask the researcher or research nurse. In addition I may contact an impartial reviewer at 707-624-7001.

Participant's Signature ____________________________ Date ____________

Parent/Legal Guardian ____________________________ If signed by other than participant, indicate relationship

Witness' Signature ____________________________ Date ____________