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The purpose of this study is to add to the scientific basis for providing subacute care in the home, by testing the effects of a post-operative nursing intervention designed to facilitate quality of life and physical/psychological well-being after diagnosis and surgery for breast cancer. A randomized clinical trial with repeated measures is examining the effects of the intervention. The **intervention** participants (n=100) receive the targeted subacute care protocol in the home from a study nurse within the first 14 post-operative days, **control A** participants (n=50) receive surgeon-ordered agency home nursing care, and the **control B** participants (n=50) receive no post-surgical nursing care. We hypothesize that, compared to the control participants, recipients of the intervention will report higher quality of life, improved surgical recovery and self-care knowledge, higher physical functioning, lower anxiety levels, fewer physical symptoms, less frequent use of health services, and lower out-of-pocket health care expenses. Trends to date indicate that the intervention women are being discharged sooner, using fewer health services post-discharge, and receiving less than half the number of nurse visits, when compared to controls, and yet are achieving comparable or better physical, emotional, and financial outcomes. Such findings can contribute to policy on these care and cost issues.

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FOREWORD

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Gwen Wyatt 9/21/99
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A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

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A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

INTRODUCTION

I. SUBJECT OF RESEARCH

The **subject** of this grant is the provision of a cost effective, highly targeted, randomized clinical trial (intervention) which provides two weeks of post-surgical nursing care in the home for women following short-stay surgery for breast cancer.

II. PURPOSE OF RESEARCH

This study is designed to address the well-documented, but unmet, physical and psychological needs of women undergoing surgery for breast cancer.^{1,2,3,4} The **purpose** of this study is to support women during the immediate post-operative phase in order to facilitate return to pre-surgical quality of life and improved physical and psychological well-being at a reasonable cost following surgery for breast cancer.

III. SCOPE OF RESEARCH

The **scope** of this study is to test the impact of a short-term (14 days post-surgical), subacute care intervention for women (21 years of age and older) who have undergone short-stay surgery (48-hours or less) for breast cancer. When compared to conventional post-surgical care, the subacute care in-home intervention is targeted to help women attain optimal recovery during their immediate post-surgical phase and assist them in regaining their pre-surgical health status prior to initiating adjuvant therapy. The broader impact of this study may include contributions to policy on length of stay for breast cancer surgery, dose of post-surgical nursing care needed, the protocol of care that is most effective for desirable outcomes, and standardizing customary costs for care.

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

BODY

I. STATEMENT OF WORK (As Submitted with Original Proposal)

YEAR	TASK	TIME PERIOD	ACTIVITIES
I	Task 1	Pre-funding Period	Orient physicians to study at all sites.
I	Task 2	Months 1 - 6	Clear IRBs of all agencies. Recruit and train research personnel.
I	Task 3	Months 7 -12	Begin participant recruitment, intervention, and data collection. (n=25)
II	Task 4	Months 13 - 18	Continue participant recruitment, intervention, and data collection. Monitor accrual. (n=50)
II	Task 5	Months 19 - 24	Continue participant recruitment, intervention, and data collection. Monitor accrual. (n=50)
III	Task 6	Months 25 - 30	Continue participant recruitment, intervention, and data collection. Begin data entry. (n=50)
III	Task 7	Months 31 - 36	Continuing recruitment, intervention, and data collection. Accelerate recruitment if necessary to account for any participants who do not complete intervention. (n=50)
IV	Task 8	Months 37 - 42	Continue recruitment if needed (n=25). Complete data entry on computer. Begin preliminary data analysis.
IV	Task 9	Months 43 - 48	Complete statistical analysis. Prepare research reports. Prepare manuscript for publication.

A. Tasks - Years I & II

See Year I and Year II Annual Reports for details on Tasks 1-5.

B. Tasks - Year III

1. Task 6, Months 25-30, Continue participant recruitment, intervention, and data collection. Begin data entry (n=50). A total of **33** participants were recruited into the study during this time period. This number includes 25 participants from the Lansing sites, 3 from St. Joseph Mercy Oakland Hospital, and 5 from our new site at William Beaumont Hospital in Troy, Michigan.

To increase the potential patient population from which to recruit, two additional surgeons were invited to participate in the study. Dr. David Kam is from our Lansing site, and Dr. Claudia Herke is from our Troy, Michigan site. Both surgeons have referred several patients to our study recruiters.

Data entry is well under way. All completed cases have been entered into our computerized system, and preliminary analyses have been conducted in preparation for the Year III Annual Report.

2. Task 7, Months 31-36, Continuing recruitment, intervention, and data collection. Accelerate recruitment if necessary to account for any participants who do not complete intervention (n=50). A total of **47** participants were recruited into the study during this time period. This number includes 34 participants from the Lansing sites, 1 from the Charlotte site, 4 from St. Joseph Mercy Oakland Hospital, and 8 from William Beaumont Hospital (Troy campus).

The total number of participants recruited for Year III of the study is **80**, excluding 2 participants who were recruited and became ineligible (due to last minute changes in surgical status which made exclusion necessary). While this number is less than the anticipated $n=100$ for Year III, we will have no difficulty reaching our total $n=200$ by the middle of Year IV. Our projections incorporated an additional $n=50$ to account for attrition. However, since we have had no attrition to date, our accrual rate is more than sufficient to meet our **total $n=200$** . The total number of participants accrued to date is **$n=190$** . Interviews have been completed on **$n=176$** , so analysis for this report will be based on this sample size ($n=176$). We credit our highly skilled nurse recruiters and nurse interveners with our successful participant retention record.

C. Continued Implementation of Policies and Procedures

Policies and procedures for the four components of our study (recruitment, intervention, interview, and chart audit) continue to be implemented as originally planned with minor adjustments made as situations arise. The guidelines developed for **recruitment** include a position description for recruiters, randomization procedure instructions, detailed instructions for the recruitment of patients and obtaining consent, pre-test questionnaires, agency consent forms, communications guidelines for interactions with agencies and patients, instructions for

computerized entry of recruitment data, study brochure, and recruitment resources. **Intervention** guidelines include the structured protocol, a position description for intervention nurses, information regarding confidentiality, universal precaution guidelines, health care referral policy, and attrition information. The **interview** guidelines include an interviewer training module, guidelines for conducting interviews, instructions for completing paper documentation (forms and letters), and instructions for the Computerized Interview Version 3 (Ci3) data entry program. The guidelines developed for the **chart audit** provide detailed instructions on obtaining diagnosis and treatment information from patients' medical charts. Detailed protocols have been developed for all components of the study, and quality assurance is conducted routinely on recruitment, intervention, interview, and chart audit materials. (See Annual Reports for Years I and II to obtain detailed information on policies, procedures, and protocols).

II. EXPERIMENTAL METHODS

A. Design (please see Appendix A)

A randomized clinical trial with repeated measures is examining the effects of a short term intervention consisting of the combination of a telephone and in-home intervention. The intervention lasts 14 days and focuses on physical and psychological subacute care following short-stay breast cancer surgery. Participants are randomly assigned to the intervention or control group. The control group is further subdivided into **control A** and **control B** depending on whether or not agency home care is ordered by their surgeon. The **intervention** group receives the in-home study protocol; the **control A** group receives agency nursing care ordered by their surgeon; and the **control B** group receives no nursing care. All three groups receive conventional post-surgical medical care.

Data are collected on all participants at 3 times over a period of 4 months (at recruitment, four weeks post-surgery, and four months post-surgery). Data collection at recruitment and four weeks post-surgery are through a combination of self-administered written questionnaires and telephone interviews with the women. The rationale for this schedule is to obtain baseline data and to compare this data with data collected after the intervention, which allows us to assess the immediate efficacy of the intervention. Data collection at four months post-surgery is in the form of a medical chart audit. Information is gathered on cancer stage, incidence of infection, seroma formation, additional surgeries, and other medical concerns that develop after initial breast cancer surgery. The four month time period allows us to see the trajectory of post-surgical follow-up care.

B. Sample

Participants are women 21 years of age and older, able to speak and read English, and receiving short-stay surgery (48 hours or less) as a first treatment for breast cancer. For this study, surgery refers to mastectomy with lymph node dissection, mastectomy without lymph node dissection, or lumpectomy with lymph node dissection. Exclusionary criteria are pregnancy, in-situ tumors, reconstructive surgery concurrent with removal of cancerous tissue, an acute episode of medically diagnosed mental illness at the time of current breast cancer diagnosis, and a home address of more than 40 miles away from the surgeon's office. Most women are stage I or II since women

with these stages generally undergo surgery as their initial treatment. English speaking skills are necessary to ensure that directions related to the data instruments and protocol teaching are understood. A total of 200 complete data sets are targeted for inclusion during the grant period. We anticipated over sampling in order to account for attrition, and to secure 200 full data sets. However, we have had minimal data loss (i.e. one post-test interview), so we will easily reach the 200 necessary for final analyses.

C. Recruitment

Sixteen surgeons are currently providing potential recruits to the study. A target goal of 5 to 7 participants per month has been set to meet the accrual objective of the grant. This recruitment goal allows for decreased accrual through winter holiday times and summer vacation periods. Recruitment procedures continue as stated in the Year I and Year II Annual Reports. Women are initially introduced to the study by a brochure written in lay language. This is followed up by a nurse recruiter who gives the women detailed information about the study (Please see Year I and II Annual Reports for details).

D. Accrual

The accrual of participants has been successful despite the short window of time between diagnosis and surgery. Of the women who have been contacted about participating in the study, **80%** have been successfully accrued. Our attrition rate is $n=0$ with one anomaly where the post-test data was not obtainable due to inability to contact the participant. In addition, two participants consented but became ineligible. We attribute the success of accrual to the fact that all study recruiters are registered nurses who are well informed about breast cancer, the surgical process, and other health issues about which women may have concerns. Recruiters are also instructed to consider the psycho-social issues facing cancer patients and employ empathy and active listening during recruitment.

E. Randomization

Once accrued and baseline data are collected, women are randomly assigned to the intervention or control groups. The recruiter telephones the campus research office, where a research assistant selects the next randomized card for that community site. The research assistant provides the recruiter (intervention group only) with the name of the nurse intervener assigned to the participant. To date, the randomization procedure has worked well.

F. Control Group

The control group has been further divided into two subgroups (**Control A** and **Control B**), since some surgeons order an agency home care nurse when their patients are assigned to our control group. This plan to consider two subgroups (**A** and **B**) within our control sample was anticipated and outlined in our Year I Annual Report. **Control A** participants receive conventional post-operative medical care and surgeon-ordered home care provided by an agency nurse. **Control B** participants receive only conventional post-operative medical care following surgery, without any home nursing care.

At the conclusion of participation in the study (3 to 5 weeks post-surgery), all control participants (groups A and B) receive the same resource packet that the **intervention** group received during their participation, and they also receive a \$10 check for contributing to the study. Through informal comments at the end of the interview, control participants have indicated the benefits gained by participating in the study. A common acknowledgment is that the comprehensive interview allows them to look at their cancer experience more holistically and to "put everything into perspective."

G. Intervention Group

The subacute care intervention is accomplished through a minimum of four contacts (two phone calls and two home visits) by a nurse intervener. The first phone contact is made within the first post-discharge day to assess any immediate needs and to schedule the first home visit. The first visit focuses on **physical** issues related to surgery, symptoms, wound and drain care, and quality of life assessment. The second phone contact occurs between the first and second in-home visits to provide an ongoing link to the health care system, assess physical and psychological needs, and to schedule the second visit. Women are also encouraged to contact their intervention nurse by pager between visits if needs or questions arise. At the second visit, the intervention focuses upon **psychological** issues, provides follow-up on physical concerns and education regarding breast self exam, arm range-of-motion exercises, and lymphedema prevention. Information on community resources is also provided with the goal of increasing access to opportunities for ongoing resources and support. Finally, one or two additional phone contacts or visits by the nurse intervener are sometimes necessary during the two week period following surgery to ensure a timely return to pre-surgical activities.

The intervention continues to run smoothly and appears to be meeting women's needs. A high level of satisfaction from participating surgeons has been noted as evidenced by zero attrition of surgeons, and the addition of two surgeons this year.

H. Intervention Protocol

While the protocol consists of a minimum of two telephone calls and two in-home visits for each woman in the intervention arm of the study, some women may receive additional encounters if assessed as necessary by the study nurse. All protocol steps are covered by the nurse during the first fourteen post-operative days in the participant's home. The intervention protocol continues successfully as in Years I and II. Please see the Year I Annual Report for details on the protocol.

I. Data Collection (please see **Table 1** for data collection schedule and instruments)

Data are collected at 3 points over a four month period: at entry into the study (baseline), at 4 weeks post-surgery, and at 4 months post-surgery. Baseline data are collected from all participants at the time of recruitment and prior to randomization. Data are collected by a nurse from the patient's medical records and by a self-administered instrument which is completed by the participant prior to surgery. Once the nurse intervener completes the intervention with a participant, she contacts the research office so the participant can be assigned to a nurse interviewer for the telephone interview data collection which occurs four weeks after surgery.

The 4-week data collection occurs after the completion of the intervention and prior to re-entry into the formal health care system for adjuvant therapy. Data are collected by a one hour telephone interview with the participant which is conducted by one of four study nurses. The nurse who conducts the interview is never the same nurse who recruits the patient or provides the intervention. This is done to minimize potential bias across roles on the grant. The 4-week data provide information on the immediate effectiveness of the intervention. In some cases, women are referred for chemotherapy as early as three weeks post-surgically. We have allowed for a variation of one week before or after the standard four week data collection point, which allows for a range between three to five weeks post-surgery for the interview to be conducted. In most cases, this added flexibility to our interview time-frame allows us to conduct the post-test interview prior to the women commencing adjuvant therapy.

The 4-month data collection is a medical chart audit conducted by a study nurse while recruiting new patients at participating sites. By combining the recruitment and chart audit tasks, the nurse reduces the number of trips to the surgical practice sites and saves time and resources. Information on clinical measures (such as stage of disease), return visits to the surgeon, further surgeries, and complications is gathered through the audit. These 4-month data provide information on the post-protocol medical events encountered and needs of women following breast cancer surgery.

J. Data Analysis

1. Baseline evaluation. Frequency distribution and measures of central tendency and variability were calculated for all variables of interest. The variables can be grouped into four broad categories as 1) Physical; 2) Psychological; 3) Quality of Life; and 4) Costs. Within each category several individual measures were analyzed as well. The baseline comparisons were done to evaluate if the groups were the same on demographic and other variables that could impact the outcome variables to be evaluated post-intervention. The statistical methods used to assess for these differences were modified for two reasons: 1) The control group was separated into **Control A** (conventional post-operative medical care **plus** surgeon-ordered home care provided by an agency nurse) and **Control B** (only conventional post-operative medical care); and 2) our initial plan to adjust for possible site differences was not applicable since 149 of the 176 subjects were recruited from the Lansing sites while only 15 were from St. Joseph Mercy Oakland Hospital, 10 were from William Beaumont Hospital, and 2 were from Hayes Green Beach Hospital. Consequently, for all continuous variables, one-way analyses of variance (ANOVA) was used to assess for baseline differences when comparing all three groups, or a two sample t-test was used when the two control groups were combined and compared to the intervention group.⁵ If the assumptions of normality and equality of variances were not satisfied, we used non-parametric equivalents of these two tests. If differences were observed, analysis of covariance was used for the post-intervention comparisons.⁵ For the discrete variables, we used the chi-square test for comparison of distributions in proportions across several levels of categorical variables in the two or three groups as appropriate, for a given comparison.^{6,7}

2. Intervention evaluation. The primary outcome variables of interest post-intervention were the various aspects of physical functioning and quality of life for the patients. We hypothesized that the intervention group would have fewer physical functioning limitations and higher quality of life, than the non-intervention group. For both instruments (Functional Status and Quality of Life), the outcome measures evaluated included the overall summary value for each instrument as well as the single items which comprise the summary value on each scale. The overall measures were treated as continuous and the individual items on the Likert scale were tested for changes in distribution of proportions. For analysis of the continuous variables, we used both one-way analysis of variance (ANOVA) and analysis of covariance (ANCOVA). In evaluating anxiety, the post-intervention comparisons were adjusted for the appropriate pre-intervention values.⁵ Similarly, in evaluating the quality of life measures, ANCOVA was used in order to adjust for the baseline quality of life levels. The conclusions from the analysis of covariance for both anxiety and quality of life measures remained the same as with two sample and paired t-tests. Consequently, in this report, we present results based on two-sample and paired t-test comparisons since they provide a clearer interpretation. In all our analysis, no adjustments were made for community sites, since the majority of our subjects were from our Lansing, Michigan site.

All of the above mentioned analyses were carried out in SAS⁸ or SPSS⁹ statistical packages available to the investigators on their office computers.

III. RESULTS

The results presented in this Year III annual report are very consistent with the Year II reported results. With the increased sample size of this report, however, we were also able to explore some of the data with the use of more sophisticated statistical tools (linear and logistic regression). The following results are presented in relation to the Statement of Work (see page 2), and the specific aims of the study. The specific aims are:

- 1. Improved surgical recovery and self-care knowledge**
- 2. Higher functional status (ADLs)**
- 3. Fewer symptoms**
- 4. Lower anxiety levels**
- 5. Higher quality of life**
- 6. Less frequent use of health services**
- 7. Fewer out-of-pocket payments for health services**

We currently have **190** participants enrolled in the study. This report provides preliminary data on **176** women who have completed the study, with **88** participants in the **intervention** group, **49** in the **control A** group, and **39** in the **control B** group. Data are collected at baseline (pre-surgery) and approximately four weeks after surgery. (Please see **Table 1** for a list of the data collection instruments and schedule.)

A. Pre- and Post-Test Interview Data

1. Demographics (please see Table 2)

Between group differences on categorical variables (e.g., race, marital status) were assessed using chi-square analysis for contingency tables, while group differences for continuous variables (i.e. income and age) were assessed using one-way analysis of variance (ANOVA). There were no significant differences between the three groups on any of the demographic variables; therefore the following data reflect the total sample. The majority of women were Caucasian (92.6%), married (60.8%), had at least some college education (70.5%), and were employed prior to surgery (61.4%). The mean age of the sample was 56 years. The average annual household income was \$53,504 (extreme outliers were omitted, e.g., a millionaire). The majority of women had a lumpectomy with axillary node dissection (76.1%).

2. Surgical Recovery and Self-Care Knowledge

a. *Antibiotic Use to Prevent or Treat Infection* (please see Table 3): Between group differences on antibiotic use were assessed using chi-square analysis. There were no significant differences found between groups. The majority of women did not use antibiotics (75.6%) following their surgery. Of those who did use antibiotics, 69% of the women used them to prevent infection, while 31% used them to treat infection. The **intervention** group had the highest percentage of antibiotic use to prevent infection (73.9%) and the lowest antibiotic use to treat infection (26.1%). The **control B** group had the highest percentage of antibiotic use to treat infection (50%).

b. *Surgical Arm Range-of-Motion (ROM) Exercises* (please see Table 4-A): Knowledge regarding range-of-motion (ROM) exercise was evaluated in terms of education received (yes/no) and the number of times taught. Both chi-square analysis and one-way analysis of variance (ANOVA) were used to assess for between group differences. Among **intervention** participants, a significantly greater proportion reported receiving education on ROM exercises ($p < .001$), when compared to control A and B participants. Further, among those who reported receiving education, **intervention** participants received a significantly greater number of teaching sessions ($p < .04$), when compared to control A and B participants.

c. *Breast Self-Exam (BSE)* (please see Table 4-B): Differences in BSE knowledge (yes/no) and technique (checking for breast lumps and use the pads of the fingers, OR use the pads of the fingers and check the under arm nodes) between groups were assessed using chi-square analysis. No significant differences were found. When responding to questions on BSE knowledge, 97.7% of **intervention** participants, 98.0% of **control A** participants, and 92.3% of **control B** participants reported understanding the procedure. When asked about the techniques used for BSE, 96.5% of the **intervention** group, 89.6% of the **control A** group, and 94.4% of the **control B** group reported using the technique of checking for breast lumps and using the pads of the fingers. For the technique of using the pads of the fingers and checking the under arm nodes, 88.2% of the **intervention** group, 79.2% of the **control A** group, and 86.1% of the **control B** group reported using the technique.

d. *Lymphedema Prevention* (please see Table 5): Lymphedema prevention was measured in terms of education received (yes/no) and the number of times taught. Both chi-square analysis and one-way analysis of variance (ANOVA) were used to assess for differences in lymphedema prevention. Among the **intervention** participants, a significantly greater proportion reported receiving education on lymphedema prevention ($p<.001$), than the other two groups. Further, among those who reported receiving education, across the three groups, **intervention** participants received the greatest number of teaching sessions ($p<.04$).

3. Functional Status (ADLs)

a. *Frequency of Limitations* (please see Table 6): Before and after surgery functional status data were self-reported by women, and collected during the post-surgical interview. Participants were questioned about 23 possible limitations in functional status on a three point scale ranging from “not limited at all” to “limited a lot.” For the 23 functional activities, participants were asked to first recall their functional level prior to surgery, and then to report their current post-surgical level. Chi-square analysis was used to assess for between group differences at both time periods. No significant differences were found between groups for either time period; however, all three groups reported greater limitation four weeks after surgery. The five most frequently reported limitations post-surgery (common across all groups) were in vigorous activity, reaching into a cupboard, moderate activity, pushing heavy objects, and lifting over 10 pounds. Vigorous activity was the most commonly reported limitation among all three groups. Within group differences from before to after surgery were assessed using paired sample t-tests. All comparisons were statistically significant ($p<.001$).

b. *Severity of Limitations* (please see Table 7): For the five most commonly reported limitations by all groups, we further assessed the severity of these limitations using the chi-square analysis. No significant between group differences were found. However, for vigorous activities and pushing heavy objects, a greater proportion of **intervention** participants reported no change in the severity of the limitation from pre- to post-surgery when compared to the control groups. Conversely, **intervention** participants also had the lowest proportion who experienced an increase in severity of limitation from pre- to post-surgery on these same two activities. For three of the five most commonly experienced limitations, the **control B** group had the largest proportion of participants experiencing limitation in vigorous activity (80.6%), pushing heavy objects (84.0%), and lifting objects over 10 pounds (95.2%).

Considering the entire sample through the use of logistic regression, we found that women who reported higher quality of life pre-surgery, had a significantly greater chance of experiencing limitations post-surgery on moderate activities ($p<.02$), pushing heavy objects ($p<.02$), lifting objects over 10 pounds ($p<.004$), and reaching into a cupboard ($p<.002$). In addition, older women had a significantly greater chance of experiencing limitation after surgery on vigorous activities ($p<.02$) and moderate activities ($p<.005$). Women with at least some high school education, had a significantly lower chance of experiencing post-surgical limitation on vigorous activities ($p<.02$).

4. Symptoms Experienced Following Surgery

a. *Frequency* (please see **Table 8**): Participants were asked to report on their symptom experience following surgery. They were first asked if they had experienced any of the 21 listed symptoms (yes/no) during the last two weeks. If they had experienced a symptom, they were then asked to rate the severity on a three point scale (mild, moderate, or severe). To compare for possible differences in the mean number of symptoms experienced within each group, the total number of symptoms experienced was calculated for each participant. This continuous variable was assessed using one-way analysis of variance (ANOVA). For specific symptoms, a chi-square test for contingency tables was used to compare the severity of selected symptoms between groups. The mean number of symptoms reported by each of the three groups (**intervention**, **control A**, and **control B**) was not significantly different. The four most common symptoms (reported by 60% or more of each group) were pain, fatigue, numbness/tingling, and limitation in surgical arm range-of-motion. When compared to the control groups, the **intervention** group had the greatest proportion of participants reporting the least severe (mild) level of pain, fatigue, and numbness/tingling four weeks after surgery. Additionally, the **intervention** group had the lowest proportion of participants reporting limitation in surgical arm range-of-motion.

b. *Degree of Limitation* (please see **Table 9**): Of those who experienced the four most frequently reported symptoms following surgery, all were asked to rate the extent to which each symptom limited their regular daily activities on a five point scale (not at all, small extent, some extent, great extent, very great extent). Between group differences in the degree of limitation experienced were assessed using chi-square analysis. No statistically significant differences were found. However, **intervention** participants, when compared to the control A and B participants, reported the highest proportion in the no limitation ("not at all") category for pain, numbness/tingling, and surgical arm range-of-motion four weeks after surgery.

Considering the entire sample through the use of linear regression, we found that women who were widowed or married reported a significantly lower number of symptoms after surgery, than women who had never married ($p < .001$ and $p < .05$, respectively). Additionally, women with the highest overall quality of life before surgery, reported significantly fewer symptoms after surgery ($p < .001$). Women who reported the greatest number of symptoms after surgery, had a significant decrease in physical quality of life after surgery ($p < .001$).

5. Anxiety (please see **Table 10**)

State anxiety was measured for all participants before and after surgery. The instrument consisted of 20 items, which were rated on a 1 to 4 scale, where 1 equaled least anxiety and 4 equaled most anxiety. Responses for all items were then summed to create a total state anxiety score. Between group differences for both pre- and post-surgery scores were assessed using one-way analysis of variance (ANOVA). No between group differences were found. Paired sample t-tests were run to compare pre- and post-surgery scores within each group. Within group comparisons revealed a significant decrease in anxiety for all 3 groups from before to

after surgery. However, women in the **intervention** group reported the greatest decrease in anxiety, as well as the lowest level of anxiety four weeks after surgery when compared to the control groups ($p<.001$).

Evaluating the entire sample through the use of linear regression, we found that independent of other factors (i.e., pre-surgery quality of life and pre-surgery state anxiety), women who received the **intervention** had a significantly reduced level of state anxiety after surgery, when compared with the control groups ($p<.04$).

6. Quality of Life (please see Table 11)

Quality of life was measured for all participants before and after surgery. Six subscales covered various areas of quality of life: physical well-being, family and social well-being, relationship with doctors, emotional well-being, functional well-being, and additional (breast cancer specific) concerns. The subscales consist of 2 to 7 items. All items are scored on a 0 to 4 point scale, where 0 equals the lowest quality of life and 4 equals the highest quality of life. A summed score was then created for each subscale. Between group differences were assessed for both pre- and post-surgery responses using one-way analysis of variance (ANOVA). No significant between group differences were found. For within group pre- to post-surgery comparisons, paired sample t-tests were used. All three groups reported a significant improvement in emotional well-being ($p<.005$); whereas the **control A** participants reported a significant decline in physical well-being ($p<.005$) from pre- to post-surgery. The **intervention** group showed a significant improvement from pre- to post-surgery in two additional areas of quality of life: social/family well-being ($p<.02$), and additional breast cancer specific concerns ($p<.005$).

Analyzing the entire sample through the use of linear regression, we found that independent of other factors (i.e., symptoms, age, and family caregiver), women who received the **intervention**, had a significant improvement in emotional quality of life after surgery, when compared to control participants ($p<.02$).

7. Use of Health Services (please see Table 12)

The length of hospital stay and utilization of six health services by the three groups within four weeks post-surgery were compared using the chi-square test for categorical variables and one-way analysis of variance (ANOVA), or its non-parametric equivalent for continuous variables. The number of hours after surgery that women were discharged from the hospital was calculated by subtracting admission date/time from discharge date/time. The majority of the total sample (89.8%) were discharged within the anticipated 48 hours or less after surgery. A higher percentage of **control** participants (**A & B combined**) exceeded the 48 hour stay after surgery (14.8%), when compared to the **intervention** participants (6.8%). In addition, the **intervention** group had a significantly lower mean hospital stay ($M=19.25$ hours) when compared to the control groups ($p<.03$).

All participants were asked about six health services they had utilized since surgery. Women who received the **intervention** reported the lowest utilization on 4 of the 6 services

(laboratory, primary care, emergency room, and re-hospitalization) when compared to the control groups. In addition, the study nurses made an average of 2.76 home visits per **intervention** participant, which was significantly fewer than the **control A** participants who received an average of 6.82 home visits from agency nurses ($p<.001$).

8. Use of Complementary Therapies (CTs) (please see Table 13)

The use of 19 CTs for the treatment of breast cancer were assessed with dichotomous (yes/no) answer choices. To test for between group differences on the use of CTs, chi-square analysis was used. Approximately 50% or more of each group reported using at least one CT to address their post-breast-cancer-surgery needs. The mean number of CTs used by **control A** participants was significantly higher ($p<.03$) than the mean number used by the other two groups. Further, a significantly greater proportion of the **control A** participants reported using special vitamin therapy and therapeutic massage ($p<.04$). The most frequently used therapy by all three groups was special vitamin therapy. When looking at the variety of therapies used, the **intervention** group used 13 different types of therapies, **control A** used 11 types of therapies, and **control B** used 9 types of therapies.

9. Out-of-Pocket Expenses Following Surgery (please see Table 14)

Participants were asked to estimate their out-of-pocket costs in five areas: complementary therapies, medications, special supplies (e.g., dressings for the surgical wound), additional costs (e.g., travel expenses to doctor appointments), and total estimated out-of-pocket costs incurred over the four week period following surgery. One-way analysis of variance (ANOVA) was used to assess for between group differences in out-of-pocket costs by the three groups. There were no significant differences found between groups. The additional costs category proved to be most expensive for all three groups, while the **control B** group incurred the greatest amount of expense in three of the five areas assessed: Additional expenses ($M=\$291.56$), medication expenses ($M=\$20.22$), and total out-of-pocket expenses ($M=\$231.08$).

B. Intervention Protocol Data

Intervention protocol data is obtained only for the **intervention** group; therefore this portion of the report is not a comparative analysis with the **control** groups.

1. Demographics Related to the Protocol Intervention (please see Table 15)

As mentioned earlier, the mean number of home visits per participant was 2.76 visits, and the mean number of phone contacts was 4.71. In terms of nursing care time, the mean amount of time spent providing direct nursing care was 55.74 minutes per visit; the mean amount of time spent per telephone encounter was 9.30 minutes in direct assessment and consultation between patient and nurse; and an additional mean of 1.24 minutes was spent on coordination of care with other health professionals via telephone. Record-keeping per home visit averaged 38.89 minutes.

2. Most Frequently Occurring Nursing Diagnoses (please see Tables 15 & 16)

For the overall group of participants (n=96), a total of 25 diagnoses (problems) have been utilized with a mean of 14.53 diagnoses per participant. Thirteen of the diagnoses are included in our standard protocol. The remaining 12 have been opened to meet the individual needs of the various participants. Please see Table 16 for a list of the most frequently used diagnoses.

IV. DISCUSSION

The following discussion is based on a sample size of n =176. It is presented in relation to the Statement of Work (see page 2), the specific aims, and the hypothesis of the study.

A. Specific Aims and Hypothesis

Our subacute care in-home nursing intervention is targeted to help women attain optimal recovery during the two week period immediately following short-stay surgery for breast cancer, and assist them in regaining their pre-surgical health status prior to initiating adjuvant therapy. This study is testing the hypothesis that when compared to women who are undergoing breast cancer surgery and receive conventional post-surgical care, recipients of our subacute care intervention will report: 1) Improved surgical recovery and self-care knowledge, 2) higher functional status (ADLs), 3) fewer symptoms, 4) lower anxiety levels, 5) higher quality of life, 6) less frequent use of health services, and 7) fewer out-of-pocket payments for health care services.

B. Post-Test Interview Data Discussion

1. Demographics

Since there were no significant differences between the three groups (**intervention**, **control A**, **control B**) on demographics, all groups were combined and demographics are reported as a total sample. This similarity among groups was anticipated due to our randomization process. The majority of the sample was Caucasian, married, middle-aged women of moderate income and relatively high education, who underwent lumpectomy with axillary node dissection as their initial treatment for breast cancer.

2. Surgical Recovery and Self-Care Knowledge

a. Infection Status and Antibiotic Use: Women who had a nurse, whether in the **intervention** group or the **control A** group, were more likely to receive preventive use of antibiotics. Additionally, the **intervention** participants were most likely to avoid developing an infection. The prevention of infection is key to recovery from breast cancer, since even a mild infection can later lead to the development of serious complications such as lymphedema.

b. Surgical Arm Range-of-Motion (ROM) Status: A key part of the nursing protocol for **intervention** participants is to teach and encourage ROM exercises following surgery. Currently, a significantly higher proportion of the **intervention** participants are reporting having received instruction on ROM exercises, plus more time has been spent on this education, as compared to either control group. While not yet reaching a significant level of difference, **intervention** women are reporting the lowest percentage of limitation on arm ROM, when compared to controls A and B (see Table 8).

c. *Breast Self-Exam (BSE)*: Since the knowledge results were very similar between the two groups who had a nurse (**intervention** and **control A**), it may be that having any form of nursing care can improve this knowledge. However, the **intervention** group had the greatest proportion of women reporting that they conducted the BSE using the correct techniques. While having a nurse (**intervention** or **control A**) may have helped increase knowledge, the study nurse appears to have conveyed the actual techniques most successfully.

d. *Lymphedema Prevention*: A significantly greater proportion of **intervention** participants reported receiving teaching on prevention of this serious complication. Since the majority of the sample had axillary lymph node dissection, this is critical information. It is of concern that a significantly lower proportion of women in the control groups are not receiving lymphedema information, and when no nurse is involved in care (**control B**), only about one-half of the women receive any information. Anecdotally, women report during their post-test interview that they may have been given some written materials on lymphedema, but frequently no instruction and minimal emphasis on the potential severity. Lymphedema can occur months after surgery and women must be educated on the techniques for prevention.

3. Functional Status (ADLs)

a. *Frequency of Limitations*: The three groups are reporting increased limitation four weeks after surgery related to vigorous activities, reaching into a cupboard, moderate activities, pushing heavy objects, and lifting activities that involve ten pounds or more. Since the majority of these activities are strenuous, it may take the women longer than a month to resume their pre-surgical levels of activity.

b. *Severity of Limitations*: Women without a nurse (**control B**) experienced the greatest increase in severity of limitation from pre- to post-surgery on three of the five activities (i.e., vigorous activity, pushing heavy objects, and lifting over 10 pounds). Therefore, having a nurse may begin to impact these limitations during the first 4 weeks after surgery. Clearly, most women who undergo breast cancer surgery are experiencing limitations at 4 weeks post-surgery.

In addition, since higher pre-surgery scores on quality of life led to diminished post-surgical functioning in several areas, it may be that these women held higher expectations for their immediate recovery period than was attainable. Future research needs to address the continued support of women (especially older women) past the 4 week post-surgical time period, to help with regaining physical functioning.

4. Symptoms Experienced Following Surgery

a. *Frequency and Severity*: All three groups reported experiencing a comparable number and range of symptoms. Following the trend established during Years I and II of the study, we continue to see 60% or more of participants reporting pain and fatigue as their most common symptoms, while limited arm range-of-motion and numbness/tingling are now similarly reported across all groups. The **intervention** group had the lowest proportion of women reporting limitation in arm range-of-motion, and the greatest proportion of women

reporting mild severity (compared to moderate or severe) on pain, fatigue, and numbness/tingling. We will watch to see if this trend continues during Year IV, since this may indicate that having a study nurse involved in care can help minimize symptom severity.

b. Degree of Limitation: **Intervention** women reported the highest proportion of "no limitation" 4 weeks after surgery on pain, numbness/tingling, and arm range-of-motion, when compared to the control groups. Of those who reported pain as causing some degree of limitation, the greatest percentage of **intervention** participants reported that pain limited them to a small extent, while a greater proportion of both **control** groups (**A & B**) reported that pain limited them to some extent or greater, i.e., more than a small extent. While differences are not statistically significant at this time, the study nurse appears to be managing limitations caused by symptoms more successfully than either of the control groups, with particular progress in the area of fine tuning pain management.

Based on the entire sample, women who had higher quality of life before surgery were more likely to report fewer symptoms after surgery. It is interesting to note that while women report physical limitation, they are less likely to associate symptom distress with these limitations if they had higher quality of life before surgery. This phenomena may address factors that we are not currently measuring, such as optimism.

5. Anxiety

Based on paired sample t-test results, we found a significant reduction in state anxiety from pre- to post-surgery for all three groups. This would be expected since anticipation of the surgical experience would be likely to raise anxiety for all women, and conversely, decrease anxiety once the surgical experience was behind them. However, the **intervention** group demonstrated the greatest decrease in anxiety and the lowest level of anxiety post-surgery when compared to the control groups. Further, linear regression showed that the decrease in state anxiety was significantly greater for the **intervention** group (controlling for pre-surgery state anxiety and pre-surgery quality of life) when compared to the control groups. It may be that study nurses are more focused on emphasizing emotional support as it is an integral part of our protocol of care.

6. Quality of Life

Intervention women reported a significant improvement in 3 areas of quality of life after surgery, compared to only one area of improvement for the other two groups (controls A and B). While we found a significant within group improvement for all groups on emotional well-being from before to after surgery, linear regression demonstrated that the **intervention** group had a significant between group improvement (when controlling for symptoms, age, and family caregiver) on emotional quality of life after surgery, compared to control A and B participants. Again, as with anxiety reduction, we found the greatest improvement in emotional well-being reported by women who received care from our study nurse. This may be due to the emphasis placed on emotional support and access to resources as targeted areas of our protocol. As would be expected, physical well-being showed a decline after surgery across all three groups. This can be attributed to the fact that women were only 3 to 5 weeks

out from surgery at the time of the post-test, and they were still recovering. This again, as with physical functioning findings, points to the on-going need for physical recuperative interventions that extend past the first 4 week post-surgical time period.

7. Use of Health Services

A major goal of this study is to provide cost effective, comprehensive, physical care, emotional care, and health education to women following breast cancer surgery. Initial trends demonstrate that the women in the **intervention** group are reporting the lowest percentage of primary care visits, emergency room visits, laboratory services, and re-hospitalizations after surgery, among the three groups. In addition, **intervention** women had the shortest length of hospital stay, and received less than half the number of nursing visits as compared to control A participants, with similar or better results. Our breast cancer specific protocol for post-surgical care is helping in multiple ways to reduce the cost of breast cancer care.

8. Complementary Therapies (CTs)

It appears that the majority of breast cancer patients are using complementary therapies in addition to customary medical care. We realize that CTs are becoming a national trend among cancer patients. It is interesting to note that **control A** participants seem to be the most involved in supplementing their care with CTs since they are reporting the highest frequency of visits. This higher use may be an attempt to supplement conventional health care; whereas, the **intervention** women are exploring the largest number of different types of CTs. Based on the expressed interest by our sample, this is an area where research is needed to determine the efficacy of various CTs with breast cancer patients.

9. Out-of-Pocket Expenses

As mentioned in the annual reports for Years I and II, participants continue to be reluctant to discuss finances. Also, they often have not received their final bills when we conduct our interview at 4 weeks post-surgery. We are in the process of conducting follow-up phone calls at 2-3 months after surgery to enrich our cost data. Based on our data, the **control B** group, who did not have any form of nursing care, incurred the greatest expense in three areas. Perhaps having a nurse helps women reduce personal costs through greater self-care education, and being more aware of resources in the community, which reduces the need for out-of-pocket expenses for supplies and medication.

C. Intervention Protocol Data Discussion

1. Demographics Related to the Protocol Intervention

When comparing our intervention data with our post-test interview data, we are able to begin to see some differences between our **control A** and **intervention** participants. Consistent with the findings for Years I and II, the **intervention** participants are requiring less than half the number of home visits when compared to **control A** participants who receive agency home care. This may be partially accounted for by the fact that our **intervention** nurses provide a very targeted self-care protocol during their visits, rather than performing care for the woman.

This approach encourages independence and self-care competency for women in the **intervention** arm of the study. In addition, the **intervention** nurses make an average of 5 telephone contacts to the women, which assists the women in managing their own care. Our study is documenting the optimal amount of nursing care needed in the first two weeks following breast cancer surgery to achieve the most desirable outcomes. While we do not have information on agency home care in terms of the amount of time spent in the home per visit, record keeping, and coordination of care by the nurses, we feel that the less than one hour per home visit spent by our intervention nurses, along with the 39 minutes of record-keeping time is very reasonable and cost effective.

2. Nursing Diagnoses

Our standardized protocol provides for assessment of seven major nursing diagnosis categories which are specific for the post-surgical breast cancer patient: pain, fatigue, constipation, anxiety, quality of life, incision care, and health education needs. In addition to the protocol diagnoses, our home care nurses individualize their assessment to each woman's needs. Some of these additional areas of need deal with nausea, community resource needs, depression, and education regarding potential seroma formation. The additional nursing diagnoses, at this time, appear to be addressing unique needs of individual women, and we will continue to assess these extra needs on a per participant basis.

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

KEY RESEARCH ACCOMPLISHMENTS

Among all adult women in our study who have had a post-surgical agency/hospital stay of 48 hours or less ($M=21.97$), we have investigated 3 types of follow up care: 1) our targeted post-surgical nursing in-home care intervention referred to as the "subacute care intervention"; 2) surgeon-ordered agency nursing care in the home; and 3) no nursing care after discharge. We have found the following:

- A greater number of women who received the targeted "subacute care intervention" reported a decrease in the use of health services (e.g., primary care, laboratory, emergency room, and re-hospitalization), and thus a decrease in out-of-pocket and insurance-based costs.
- "Subacute care intervention" participants received an average of three home visits, which was significantly fewer than the control participants (agency nursing care group), who required an average of seven home visits to attain comparable physical, emotional, and educational outcomes.
- Women who received the targeted "subacute care intervention" reported a significant decrease in state anxiety, and a significant increase in quality of life in the areas of emotional well-being, social/family well-being, and concerns related specifically to breast cancer.
- A significantly greater number of women who received the targeted "subacute care intervention" reported receiving teaching on surgical arm range-of-motion exercises and protective measures against lymphedema, than those who received agency nursing care or no nursing care in the home. Additionally, a lower proportion of the women who received the targeted "subacute care intervention" reported experiencing limitation in surgical arm range-of-motion.
- Women in the "subacute care intervention" reported lower symptom severity on key symptoms (e.g., pain, fatigue, and numbness/tingling) when compared to those who received agency nursing care or no nursing care. Of those participants who experienced the symptoms of pain, numbness/tingling, and limitation in arm range-of-motion, a greater proportion of women receiving the "subacute care intervention" reported that these symptoms caused "no limitation" in activities of daily living.
- Women receiving the "subacute care intervention" had the lowest reported use of antibiotics for infection.
- A greater proportion of women in the "subacute care intervention" reported using the correct techniques for breast self exam (BSE).
- Women who did not receive post-surgical nursing care, reported the highest level of out-of-pocket cost in 3 of 5 areas (medications, additional expenses, and total out-of-pocket expenses), when compared to the groups who had a study or agency nurse.

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

REPORTABLE OUTCOMES

Presentations, abstracts, a graduate student thesis, and a grant proposal based on this research and occurring during Year III of the grant (September 1998-September 1999) are listed below.

I. PRESENTATIONS (See **Appendix B** for Grant Productivity Report & **Appendix C** for P.I. Publications)
Rovoll, M.D. & Wyatt, G.K. (1999, May 13). The Challenges of Quality Assurance in Data Entry. Paper presentation for the 22nd Annual Michigan Family Practice Research Day Conference, Michigan State University, East Lansing, MI.

Beckrow, K.C., Wyatt, G.K., Given, C.W., & Given, B.A. (1999, April 20). A Conceptual Model for an In-Home Nursing Intervention following Short-Stay Surgery for Breast Cancer. Poster presentation for the Seventh Annual Greater Lansing Nursing Research Day, Ingham Regional Medical Center, Lansing, MI.

Wyatt, G.K. (1998, November 20). Nurse Sensitive Outcomes for the Short-Stay Breast Cancer Patient. Paper presentation for Oncology Nursing Society, State-of-the-Knowledge Conference on Nurse Sensitive Outcomes, Pittsburgh, PA.

II. ABSTRACTS (See **Appendix D** for Grant Abstracts)

Rovoll, M.D. & Wyatt, G.K. (1999, May). The Challenges of Quality Assurance in Data Entry. Michigan Family Practice Research Day. Published in Proceedings Book, p. 8.

Beckrow, K.C., Wyatt, G.K., Given, C.W., & Given, B.A. (1999, April). A Conceptual Model for an In-Home Nursing Intervention following Short-Stay Surgery for Breast Cancer. Seventh Annual Greater Lansing Nursing Research Day. Published in Proceedings Book.

Wyatt, G.K., Given, B.A., & Given, C.W. (1998, November). Nurse-Sensitive Outcomes for the Short-Stay Breast Cancer Patient. Oncology Nursing Society's State-of-the Knowledge Conference on Nurse-Sensitive Outcomes. Published in Proceedings Book, p.35.

III. GRADUATE STUDENT THESIS (See **Appendix E** for Thesis Abstract)

Bloomfield, M. (1999). The Effects of Early Versus Delayed Exercise on Seroma Formation and Range-of-Motion Recovery in Short-Stay Breast Cancer Surgery Patients.

IV. GRANT PROPOSAL (See **Appendix F** for Proposal Abstracts)

Wyatt, G.K., Collins, C., & Bradley, C. (1999, July). Improving Outcomes Through a Supportive Intervention: A Continuum of Holistic Care. Submitted to the Department of Defense.

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

CONCLUSIONS

I. SUMMARY OF RESULTS

Overall, the **intervention** women are being discharged sooner, using fewer health services post-discharge, and receiving less than half the number of nurse visits, when compared to controls, and yet are achieving comparable or better physical, emotional, and educational outcomes. From the data obtained thus far, women in the **intervention** arm of the study are receiving follow-up care in the home on the average of 2.76 visits and 4.71 **phone calls** in the first 14 days post-operatively by a study nurse. Our **control A** women, who receive agency home care, are currently receiving **over twice the number of home visits** as our intervention participants. This year, with our larger sample, we are seeing more areas where our **intervention** group is achieving the most favorable outcomes. The major differences are improvement in quality of life, symptom experience, anxiety, education regarding range-of-motion exercises, breast self-exam, and the prevention of lymphedema, and cost savings, including fewer visits to primary care providers, emergency rooms, laboratories, and re-hospitalization. The area where all women are reporting limitation at 4 weeks after surgery is in functional status. They remain limited in range-of-motion and activities of daily living (ADLs) and all report a lower physical quality of life. Future research must address the physical functioning and mobility needs that continue beyond 4 weeks after surgery.

II. EVALUATION OF KNOWLEDGE AS A SCIENTIFIC PRODUCT

The findings from our work could translate into national policy for discharge planning in terms of length of hospital stay, standard of care for subacute post-surgical needs, optimal amount of nursing care necessary to achieve favorable outcomes, and associated costs.

A. Policy on Length of Stay: Our research demonstrates that an average of 19.25 hours is adequate to hospitalize women for breast cancer surgery, when they receive a subacute care nursing intervention in the home following discharge. Rather than the current emphasis on length of hospital stay, we propose a shift in the focus to high quality, standardized nursing care in the home.

B. Policy on Standard of Care: A targeted subacute care protocol can achieve desirable physical, psychological, and educational outcomes post-surgically in the home, while reducing the use of costly medical services (i.e., primary care, emergency room, laboratory services, and re-hospitalizations).

C. Policy on Dose of Post-Surgical Home Care: A nursing care dose of 2.76 home visits (utilizing the subacute care protocol) can achieve comparable or better physical, psychological, and educational outcomes than over twice this number of visits by an agency nurse. Cost savings would be expected to be similarly proportional.

D. Policy on Necessary and Allowable Out-of-Pocket Costs: Utilizing a targeted nursing-based protocol following discharge for breast cancer surgery can control and standardize reasonable and necessary out-of-pocket costs for patients.

III. FUTURE WORK

In order to further the research of the current DoD study, Dr. Wyatt submitted a new proposal to the Department of Defense which, in addition to providing the targeted subacute care intervention (to produce a common baseline), is aimed at addressing the needs of women following surgery and during the adjuvant therapy phase of care. This project will address the physical limitation and lower physical quality of life reported in the current study. We will test the effects of a supportive care intervention that incorporates yoga to address the physical limitations such as range of motion and activities of daily living. Along with the yoga, there will be an educational component to address emotional issues, body chemistry, body image, chemotherapy, radiation, and financial considerations. We will test a standardized protocol of yoga stretches and education through a randomized clinical trial. (See **Appendix F** for Grant Proposal Abstracts.)

An additional focus for future work is on women with terminal breast cancer. These women have needs whether they are receiving palliative treatment or aggressive chemotherapy. Along with the conventional medical care that is currently available, many women are turning to complementary therapies to provide symptom control and psychological comfort. We would like to facilitate a standardized use of complementary therapies that could assist women in attaining the highest quality of life possible during their end-of-life period. (See **Appendix F** for Grant Proposal Abstracts.)

There is much that continues to be needed in the area of supportive care for women with breast cancer. We hope our work will make a substantial contribution to this goal.

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Table 1

DATA COLLECTION SCHEDULE

MEASURES	PRE-SURGERY	POST-SURGERY (4 Weeks)
Demographic Data Sheet	X	N/A
Functional Status (Modified SF-36)	X	X
Symptom Experience (Modified)	N/A	X
Healing Process	N/A	X
Anxiety (Speilberger State-Trait)	X	X
Quality of Life FACT-B	X	X
Out-of-Pocket Health Costs	N/A	X
Chart Audit (cancer stage, surgery, lymph node involvement)	N/A	X

Table 2

DEMOGRAPHICS

Intervention (n=88)												Control A' (n=49)				Control B'' (n=39)				Total Controls A & B (n=88)				Study Total (n=176)																											
n												%		n		%		n		%		n		%		n		%																							
Ethnicity																																																			
Caucasian												81		92.0%		44		89.8%		38		97.4%		82		93.0%		163		92.6%																					
Other												7		8.0%		5		10.2%		1		2.6%		6		7.0%		13		7.4%																					
Marital Status																																																			
Married												50		56.8%		35		71.4%		22		56.4%		57		64.8%		107		60.8%																					
Divorced/Separated												17		19.3%		8		16.3%		8		20.5%		16		18.2%		33		18.8%																					
Widowed												11		12.5%		4		8.2%		7		17.9%		11		12.5%		22		12.5%																					
Never married												10		11.4%		2		4.1%		2		5.1%		4		4.5%		14		8.0%																					
Employment Status																																																			
Not employed before surgery												38		43.2%		19		38.8%		11		28.2%		30		34.1%		68		38.6%																					
Employed before surgery												50		56.8%		30		61.2%		28		71.8%		58		65.9%		108		61.4%																					
--Returned to work after surgery												27		54.0%		13		43.3%		17		60.7%		30		51.7%		57		52.8%																					
--Did not return to work after surgery												23		46.0%		17		56.7%		11		39.3%		28		48.3%		51		47.2%																					
Education																																																			
Completed graduate degree												14		15.9%		7		14.3%		11		28.2%		18		20.5%		32		18.2%																					
Completed college												11		12.5%		6		12.2%		3		7.7%		9		10.2%		20		11.4%																					
Completed some college												30		34.1%		21		42.9%		14		35.9%		35		39.8%		65		36.9%																					
Completed high school												22		25.0%		12		24.5%		8		20.5%		20		22.7%		42		23.9%																					
Completed some high school												9		10.2%		2		4.1%		2		5.1%		4		4.5%		13		7.4%																					
Completed grade school												2		2.3%		1		2.0%		1		2.6%		2		2.3%		4		2.3%																					
Type of Surgery																																																			
Lumpectomy with node removal												71		80.7%		35		71.4%		28		71.8%		63		71.6%		134		76.1%																					
Mastectomy with node removal												14		15.9%		10		20.4%		11		28.2%		21		23.9%		35		19.9%																					
Simple Mastectomy												3		3.4%		4		8.2%		0		0.0%		4		4.5%		7		4.0%																					
Intervention												n		M		SD		Min-Max		Control B''		n		M		SD		Min-Max		Total Controls A & B		n		M		SD		Min-Max													
Income (\$)												69		51,528		30,201		15,000-150,000		40		53,728		29,796		15,900-140,000		32		57,484		30,392		16,500-130,000		72		55,397		29,908		15,900-140,000		141		53,504		30,007		15,000-150,000	
Age (years)												88		56.19		11.92		23-83		49		57.06		12.90		33-84		39		54.95		9.38		33-75		88		56.13		11.46		33-84		176		56.16		11.66		23-84	

Table 3

SURGICAL RECOVERY AND SELF CARE KNOWLEDGE: ANTIBIOTIC USE TO PREVENT OR TREAT INFECTION

	No Antibiotic Use		Used Antibiotics		Used Antibiotics			
	<i>Total</i>		<i>Total</i>		<i>To Prevent Infection</i>		<i>To Treat Infection</i>	
	n	%	n	%	n	%	n	%
Intervention (n=88)	64/88	72.7%	23/87	26.4%	17/23	73.9%	6/23	26.1%
Control A* (n=49)	36/49	73.5%	13/49	26.5%	9/13	69.2%	4/13	30.8%
Control B** (n=39)	33/39	84.6%	6/39	15.4%	3/6	50.0%	3/6	50.0%
Total (n=176)	133/176	75.6%	42/175	24.0%	29/42	69.0%	13/42	31.0%

*Received nursing care provided by an agency nurse

**Received no nursing care

Table 4-A

SURGICAL RECOVERY AND SELF-CARE KNOWLEDGE: RANGE-OF-MOTION (ROM) EXERCISES

	Intervention (n=88)		Control A* (n=49)		Control B** (n=39)		Total Controls A & B (n=88)					
	n	%	n	%	n	%	n	%				
Received teaching for ROM exercises	81	92.0%*	34	69.4%	27	69.2%	61	69.3%				
	Intervention (n=88)		Control A* (n=49)		Control B** (n=39)		Total Controls A & B (n=88)					
	n	M	SD	n	M	SD	n	M	SD			
Number of times ROM taught**	81	1.75	0.78	34	1.47	0.86	27	1.33	0.68	61	1.41	0.78

* $p < .001$ ** $p < .04$

Table 4-B

SURGICAL RECOVERY AND SELF-CARE KNOWLEDGE: BREAST SELF-EXAM (BSE)

	Intervention (n=88)		Control A* (n=49)		Control B** (n=39)		Total Controls A & B (n=88)	
	n	%	n	%	n	%	n	%
Knowledge of BSE	86/88	97.7%	48/49	98.0%	36/39	92.3%	84/88	95.5%
BSE Technique								
--Check for breast lumps and use pads of fingers	82/85	96.5%	43/48	89.6%	34/36	94.4%	77/84	91.7%
--Use pads of fingers and check under arm nodes	75/85	88.2%	38/48	79.2%	31/36	86.1%	69/84	82.1%

*Received nursing care provided by an agency nurse

**Received no nursing care

Table 5

SURGICAL RECOVERY AND SELF-CARE KNOWLEDGE: LYMPHEDEMA PREVENTION

	Intervention (n=88)			Control A* (n=49)			Control B** (n=39)			Total Controls A & B (n=88)		
	n	M	SD	n	M	SD	n	M	SD	n	M	SD
Received teaching for lymphedema prevention	79/83		95.2%*	31/45		68.9%	20/39		51.3%	51/84		60.7%
Number of times taught**	Intervention (n=88)			Control A* (n=49)			Control B** (n=39)			Total Controls A & B (n=88)		
	n	M	SD	n	M	SD	n	M	SD	n	M	SD
	78/83	1.97	0.97	31/45	1.68	0.94	20/39	1.40	0.68	51/84	1.57	0.85

* $p < .001$ ** $p < .04$

*Received nursing care provided by an agency nurse

**Received no nursing care

NOTE: These data pertain only to women who had axillary lymph node dissection.

Table 6

FUNCTIONAL STATUS: FIVE MOST FREQUENTLY REPORTED LIMITATIONS

Intervention (n=88)						
	Before		After		Change	
	n	%	n	%	n	%
Vigorous Activity	20/88	22.7%	71/88	80.7%	51/88	58.0%
Reaching Into Cupboard	4/88	4.5%	63/88	71.6%	59/88	67.1%
Moderate Activity	8/88	9.1%	61/88	69.3%	53/88	60.2%
Pushing Heavy Objects	18/88	20.5%	60/87	69.0%	42/87	48.3%
Lifting Objects > 10 lbs.	11/88	12.5%	57/87	65.5%	46/87	52.9%
Control A* (n=49)						
	Before		After		Change	
	n	%	n	%	n	%
Vigorous Activity	11/49	22.4%	41/49	83.7%	30/49	61.2%
Reaching Into Cupboard	3/49	6.1%	34/49	69.4%	31/49	63.3%
Moderate Activity	5/49	10.2%	36/49	73.5%	31/49	63.3%
Pushing Heavy Objects	7/46	15.2%	28/44	63.6%	21/44	47.7%
Lifting Objects >10 lbs.	9/49	18.4%	36/48	75.0%	27/48	56.3%
Control B** (n=39)						
	Before		After		Change	
	n	%	n	%	n	%
Vigorous Activity	6/37	16.2%	31/37	83.8%	25/37	67.6%
Reaching into Cupboard	2/39	5.1%	20/39	51.3%	18/39	46.2%
Moderate Activity	6/38	15.8%	27/38	71.1%	21/38	55.3%
Pushing Heavy Objects	4/38	10.5%	25/38	65.8%	21/38	55.3%
Lifting Objects >10 lbs.	1/38	2.6%	21/37	56.8%	20/37	54.1%

* Received nursing care provided by an agency nurse

** Received no nursing care

Table 7

FUNCTIONAL STATUS: SEVERITY OF LIMITATIONS

	Intervention		Control A*		Control B**		Total Controls A & B	
	n	%	n	%	n	%	n	%
Vigorous Activity								
No change in Severity from Pre to Post	20/71	28.2%	11/41	26.8%	6/31	19.4%	17/72	23.6%
Increase in Severity from Pre to Post	51/71	71.8%	30/41	73.2%	25/31	80.6%	55/72	76.4%
Reaching Into Cupboard								
No Change in Severity from Pre to Post	4/63	6.3%	3/34	8.8%	2/20	10.0%	5/54	9.3%
Increase in Severity from Pre to Post	59/63	93.7%	31/34	91.2%	18/20	90.0%	49/54	90.7%
Moderate Activity								
No Change in Severity from Pre to Post	8/61	13.1%	5/36	13.9%	6/27	22.2%	11/63	17.5%
Increase in Severity from Pre to Post	53/61	86.9%	31/36	86.1%	21/27	77.8%	52/63	82.5%
Pushing Heavy Objects								
No Change in Severity from Pre to Post	18/60	30.0%	7/28	25.0%	4/25	16.0%	11/53	20.8%
Increase in Severity from Pre to Post	42/60	70.0%	21/28	75.0%	21/25	84.0%	42/53	79.2%
Lifting Objects > 10 lbs								
No Change in Severity from Pre to Post	11/57	19.3%	9/36	25.0%	1/21	4.8%	10/57	17.5%
Increase in Severity from Pre to Post	46/57	80.7%	27/36	75.0%	20/21	95.2%	47/57	82.5%

*Received nursing care provided by an agency nurse

**Received no nursing care

Table 8

SYMPTOMS EXPERIENCED FOLLOWING SURGERY: FREQUENCY

	Mean # of Symptoms (four weeks after surgery)		Standard Deviation # of Symptoms		Min-Max # of Symptoms		Possible Range of Total Symptoms	
Intervention (n=88)	6.49		3.37		0-14		0-21	
Control A' (n=49)	6.53		3.69		0-15		0-21	
Control B'' (n=39)	6.13		3.40		0-13		0-21	
Total Controls A & B (n=88)	6.35		3.56		0-15		0-21	
Symptoms Reported by 60% or More of Each Group (four weeks after surgery)								
	Intervention (n=88)		Control A' (n=49)		Control B'' (n=39)		Total Controls A&B (n=88)	
	n	%	n	%	n	%	n	%
Pain								
No	19	21.6%	18	36.7%	13	33.3%	31	35.2%
Yes	69	78.4%	31	63.3%	26	66.7%	57	64.8%
Mild	40	58.0%	11	35.5%	14	53.9%	25	43.9%
Moderate	25	36.2%	17	54.8%	11	42.3%	28	49.1%
Severe	4	5.8%	3	9.7%	1	3.8%	4	7.0%
Fatigue								
No	25	28.4%	14	28.6%	12	30.8%	26	29.5%
Yes	63	71.6%	35	71.4%	27	69.2%	62	70.5%
Mild	34	54.0%	18	51.4%	14	51.9%	32	51.6%
Moderate	24	38.1%	17	48.6%	11	40.7%	28	45.2%
Severe	5	7.9%	0	0.0%	2	7.4%	2	3.2%
Numbness and Tingling								
No	25	28.4%	19	38.8%	8	20.5%	27	30.7%
Yes	63	71.6%	30	61.2%	31	79.5%	61	69.3%
Mild	31	49.2%	8	27.6%	14	45.2%	22	36.7%
Moderate	21	33.3%	17	58.6%	14	45.2%	31	51.7%
Severe	11	17.5%	4	13.8%	3	9.6%	7	11.7%
Limitation in Surgical Arm Range of Motion								
No	35	39.8%	18	36.7%	13	33.3%	31	35.2%
Yes	53	60.2%	31	63.3%	26	66.7%	57	64.8%
Mild	30	56.6%	13	41.9%	16	61.5%	29	50.9%
Moderate	19	35.9%	13	41.9%	9	34.6%	22	38.6%
Severe	4	7.5%	5	16.1%	1	3.9%	6	10.5%

*Received nursing care provided by an agency nurse

**Received no nursing care

Table 2

SYMPTOMS FOLLOWING SURGERY: DEGREE OF LIMITATION

	Intervention		Control A*		Control B**		Total Controls A & B	
	n	%	n	%	n	%	n	%
Pain	(n=68)		(n=31)		(n=26)		(n=57)	
Not at all	24	35.3%	9	29.0%	7	26.9%	16	28.1%
Small extent	19	27.9%	3	9.7%	5	19.2%	8	14.0%
Some extent	18	26.5%	12	38.7%	11	42.3%	23	40.4%
Great extent	6	8.8%	4	12.9%	2	7.7%	6	10.5%
<u>Very great extent</u>	<u>1</u>	<u>1.5%</u>	<u>3</u>	<u>9.7%</u>	<u>1</u>	<u>3.9%</u>	<u>4</u>	<u>7.0%</u>
Total Limitations	44	64.7%	22	71.0%	19	73.1%	41	71.9%
Fatigue	(n=62)		(n=35)		(n=27)		(n=62)	
Not at all	20	32.3%	13	37.1%	9	33.3%	22	35.5%
Small extent	16	25.8%	10	28.6%	6	22.2%	16	25.8%
Some extent	16	25.8%	7	20.0%	8	29.6%	15	24.2%
Great extent	9	14.5%	4	11.4%	3	11.1%	7	11.3%
<u>Very great extent</u>	<u>1</u>	<u>1.6%</u>	<u>1</u>	<u>2.9%</u>	<u>1</u>	<u>3.7%</u>	<u>2</u>	<u>3.2%</u>
Total Limitations	42	67.7%	22	62.9%	18	66.7%	40	64.5%
Numbness and Tingling	(n=62)		(n=29)		(n=31)		(n=60)	
Not at all	40	64.5%	15	51.7%	18	58.1%	33	55.0%
Small extent	10	16.1%	4	13.8%	5	16.1%	9	15.0%
Some extent	8	12.9%	6	20.7%	7	22.6%	13	21.7%
Great extent	2	3.2%	2	6.9%	1	3.2%	3	5.0%
<u>Very great extent</u>	<u>2</u>	<u>3.2%</u>	<u>2</u>	<u>6.9%</u>	<u>0</u>	<u>0.0%</u>	<u>2</u>	<u>3.3%</u>
Total Limitations	22	35.5%	14	48.3%	13	41.9%	27	45.0%
Limitation in Surgical Arm Range of Motion	(n=52)		(n=31)		(n=26)		(n=57)	
Not at all	16	30.8%	7	22.6%	5	19.2%	12	21.1%
Small extent	13	25.0%	10	32.3%	13	50.0%	23	40.4%
Some extent	15	28.8%	9	29.0%	4	15.4%	13	22.8%
Great extent	5	9.6%	4	12.9%	3	11.5%	7	12.3%
<u>Very great extent</u>	<u>3</u>	<u>5.8%</u>	<u>1</u>	<u>3.2%</u>	<u>1</u>	<u>3.9%</u>	<u>2</u>	<u>3.5%</u>
Total Limitations	36	69.2%	24	77.4%	21	80.8%	45	78.9%

*Received nursing care provided by an agency nurse

**Received no nursing care

Table 10

STATE ANXIETY OVER TIME

The higher the score, the greater the anxiety

Time	Intervention (n=88)			Control A' (n=49)			Control B'' (n=39)		
	M	SD	Min-Max	M	SD	Min-Max	M	SD	Min-Max
Before surgery	42.88	14.23	20-78	41.41	13.69	19-75	45.21	15.03	20-80
After surgery	34.74*	12.63	20-77	36.47**	13.25	20-63	39.03***	14.13	20-80

* $p < .001$ (within group comparison)

** $p < .002$ (within group comparison)

*** $p < .01$ (within group comparison)

'Received nursing care provided by an agency nurse

..Received no nursing care

Table 11

QUALITY OF LIFE OVER TIME

The higher the mean, the greater the Quality of Life

Intervention (n=88)						
Sub-scales	Before Surgery			After Surgery		
	M	SD	Min/Max	M	SD	Min/Max
Physical well-being	20.55	4.07	1-24	20.10	3.24	9-24
Social and family well-being	19.47	4.82	8-24	20.63**	4.02	6-24
Relationship with doctors	7.27	1.44	0-8	7.26	1.10	1-8
Emotional well-being	16.22	5.01	4-24	19.31*	4.23	3-24
Functional well-being	20.88	5.95	0-28	21.10	5.06	6-28
Additional concerns	18.34	3.96	8-26	19.80*	4.02	10-28
Control A* (n=49)						
Sub-scales	Before Surgery			After Surgery		
	M	SD	Min/Max	M	SD	Min/Max
Physical well-being	21.24	2.33	14-24	19.27*	4.89	5-24
Social and family well-being	20.39	4.40	7-24	20.78	3.48	10-24
Relationship with doctors	7.10	1.28	4-8	7.04	1.22	4-8
Emotional well-being	16.08	5.22	4-24	19.10*	4.49	6-24
Functional well-being	20.92	4.69	10-28	19.94	5.01	5-28
Additional concerns	18.31	4.12	10-26	19.39	4.61	8-27
Control B** (n=39)						
Sub-scales	Before Surgery			After Surgery		
	M	SD	Min/Max	M	SD	Min/Max
Physical well-being	20.77	3.44	13-24	19.41	4.44	4-24
Social and family well-being	20.59	4.28	8-24	21.28	3.49	11-24
Relationship with doctors	7.67	0.77	5-8	7.54	1.19	2-8
Emotional well-being	15.36	5.01	5-23	17.77*	4.77	5-24
Functional well-being	21.10	6.05	5-28	20.10	5.92	1-28
Additional concerns	18.82	4.32	9-26	19.69	4.80	8-28

* $p < .005$ (within group comparison)** $p < .02$ (within group comparison)

*Received nursing care provided by an agency nurse

**Received no nursing care

Table 12

USE OF HEALTH SERVICES: COMPARISONS ACROSS GROUPS

	Intervention (n=84)				Control A* (n=48)				Control B** (n=39)				Total Controls A & B (n=87)				Study Total (n=171)			
	n	M	SD		n	M	SD		n	M	SD		n	M	SD		n	M	SD	
Surgery	84	19.25*	10.80		48	24.39	16.54		39	24.86	12.24		87	24.60	14.69		171	21.97	13.16	
Hospital Stay (hours)																				
Total Controls A & B (n=88)																				
Services/Visits	Intervention (n=88)				Control A* (n=49)				Control B** (n=39)											
	n	%	M	SD	n	%	M	SD	n	%	M	SD	n	%	M	SD	n	%	SD	
Surgeon Post-op	88	100.0%	2.78	2.06	49	100.0%	2.98	1.83	39	100.0%	2.74	1.39	88	100.0%	2.88	1.65				
Laboratory	11	12.5%	1.82	1.33	12	24.5%	1.58	0.90	6	15.4%	1.67	1.03	18	20.5%	1.61	0.92				
Primary Care	7	8.0%	1.14	0.38	6	12.2%	1.00	0.00	6	15.4%	1.00	0.00	12	13.6%	1.00	0.00				
Emergency Room	2	2.3%	1.00	0.00	2	4.1%	1.00	0.00	4	10.3%	1.00	0.00	6	6.9%	1.00	0.00				
Re-hospitalization	7	8.0%	1.00	0.00	6	12.2%	1.00	0.00	4	10.3%	1.00	0.00	10	11.4%	1.00	0.00				
Social Worker	4	4.5%	1.00	0.00	1	2.0%	3.00	---	2	5.1%	2.50	0.71	3	3.4%	2.67	0.58				
Home Care Nurse from study nurse	88	100.0%	2.76**	0.90	---	---	---	---	---	---	---	---	---	---	---	---				
from agency service	---	---	---	---	49	100.0%	6.82	7.33	---	---	---	---	49	55.7%	6.82	7.33				

*p < .03

**p < .001

*Received nursing care provided by an agency nurse

**Received no nursing care

NOTE: Hospital Stay outliers (greater than 75 hours) were omitted from analysis.

Table 13

USE OF COMPLEMENTARY THERAPIES (CTs)

	Intervention (n=88)		Control A [*] (n=49)		Control B ^{**} (n=39)		Total Controls A&B (n=88)	
	n	%	n	%	n	%	n	%
Used one or more CTs	43/88	48.9%	33/49	67.3%	21/39	53.9%	54/88	61.4%
Variety of CTs used	13/14	93.0%	11/14	78.6%	9/14	64.3%	11/14	78.6%
	M	SD	M	SD	M	SD	M	SD
Average # of CTs per Participant	0.84	1.13	1.41*	1.43	0.90	1.00	1.18	1.27
Frequency of Therapy Use								
	n	%	n	%	n	%	n	%
Special Vitamin Therapy	26	29.5%	25	51.0%**	12	30.8%	37	42.0%
Herbal Therapy	9	10.2%	9	18.4%	4	10.3%	13	14.8%
Relaxation Audio Tapes	6	6.8%	5	10.2%	7	17.9%	12	13.6%
Special Cancer Diet	6	6.8%	2	4.1%	5	12.8%	7	8.0%
Guided Imagery	6	6.8%	4	8.2%	2	5.1%	6	6.8%
Therapeutic Massage	5	5.7%	8	16.3%**	1	2.6%	9	10.2%
Spiritual Healing	5	5.7%	7	14.3%	2	5.1%	9	10.2%
Special Cultural Therapies	3	3.4%	0	0.0%	0	0.0%	0	0.0%
Yoga Therapy	2	2.3%	3	6.1%	1	2.6%	4	4.5%
Relaxation Video Tapes	2	2.3%	1	2.0%	1	2.6%	2	2.3%
Music Therapy	1	1.3%	0	0.0%	0	0.0%	0	0.0%
Acupuncture Treatment	1	1.1%	0	0.0%	0	0.0%	0	0.0%
Therapeutic Touch	1	1.1%	2	4.1%	0	0.0%	2	2.3%
Chiropractic Treatment	0	0.0%	2	4.1%	0	0.0%	2	2.3%

* $p<.03$ ** $p<.04$

▲ Received nursing care provided by an agency nurse

▲▲ Received no nursing care

Table 14

OUT-OF-POCKET EXPENSES FOLLOWING SURGERY

	Intervention (n=88)				Control A* (n=49)				Control B** (n=39)				Total Controls A & B (n=88)			
	n	M	SD	Min-Max	n	M	SD	Min-Max	n	M	SD	Min-Max	n	M	SD	Min-Max
Complementary Therapies	43	\$21.33	37.21	\$0-150	33	\$38.33	55.27	\$0-255	21	\$11.52	16.29	\$0-50	54	\$27.91	46.03	\$0-255
Medications	62	\$17.68	26.69	\$2-180	36	\$14.19	14.05	\$2-70	32	\$20.22	36.05	\$2-192	68	\$17.03	26.71	\$2-192
Special Supplies	40	\$23.75	56.48	\$3-360	21	\$15.90	12.89	\$2-50	16	\$22.88	36.32	\$3-150	37	\$18.92	25.58	\$2-150
Additional Costs	22	\$121.00	216.52	\$3-1000	22	\$114.27	113.74	\$6-375	9	\$291.56	499.88	\$10-1550	31	\$165.74	287.02	\$6-1550
Total Out-of-Pocket	74	\$195.58	601.28	\$1-5013	43	\$123.35	134.26	\$4-611	37	\$231.08	563.43	\$2-2500	80	\$173.18	396.44	\$2-2500

*Received nursing care provided by an agency nurse

**Received no nursing care

Table 15

DEMOGRAPHIC PROTOCOL DATA: INTERVENTION PARTICIPANTS

Variable	M	SD	Min-Max
Number of visits per participant	2.76	0.90	2-6
Number of phone contacts per participant	4.71	1.77	2-12
Number of nursing diagnoses (problems) opened per participant	14.53	1.60	12-25
Home visit direct care time per visit (minutes)	55.74	22.81	10-135
Home visit record-keeping time per participant (minutes)	38.89	23.56	0-120
Telephone direct care time per contact (minutes)	9.30	7.45	0-75
Telephone coordination of care time with other health providers (minutes)	1.24	4.10	0-30

Table 16

NURSING DIAGNOSES USED: INTERVENTION PARTICIPANTS

Categories	Protocol Diagnoses	Number of Times Used
1. Pain	Pain, acute	95
2. Fatigue	Activity intolerance	92
3. Constipation	Constipation	90
4. Anxiety	Anxiety	87
5. Quality of life	Alteration in quality of life	70
6. Incision Care	Skin integrity/surgery	94
	Knowledge deficit, milk drain	88
	Knowledge deficit, empty drain	88
	Knowledge deficit, record drainage	88
	Knowledge deficit, dressing change	80
7. Health Education	Knowledge deficit, BSE	93
	Knowledge deficit, ROM affected arm	90
	Knowledge deficit, lymphedema prevention	89
Categories	Additional Diagnoses	Number of Times Used
1. Incision care	Self-care deficit, clogged drainage tube	8
	Self-care deficit, dressing change	5
	Knowledge deficit, seroma signs and symptoms	5
2. Quality of life	Activities of daily living, functional alterations	14
	Emotional alterations	5
	Social/family alterations	4
	Physical, altered	3
3. Nausea	Nausea	8
4. Depression	Depression, side effects	5
	Knowledge deficit, community resources	4
5. Fatigue	Fatigue, acute	4
6. Fever	Fever/hyperthermia	3

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

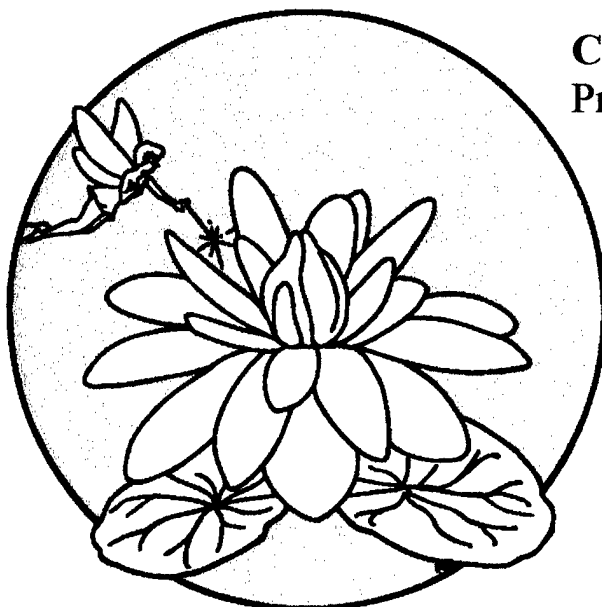
**Appendices for Year Three Annual Report
September 15, 1998 to September 14, 1999**

Funded by: **U.S. Army Medical Research
Materiel Command
Department of Defense
Grant # DAMD17-96-1-6325**

Principal Investigator:
Gwen Wyatt, PhD, RN
Associate Professor, College of Nursing

Co-principal Investigators:
Barbara Given, PhD, RN, FAAN
Professor, College of Nursing

Charles Given, PhD
Professor, College of Human Medicine



**Michigan State University
East Lansing, Michigan 48824**

A New Beginning

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

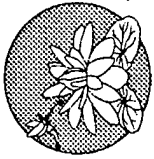
APPENDICES

Study Design	Appendix A
Grant Productivity Report	Appendix B
1998-1999 P.I. Published Journal Articles	Appendix C
1998-1999 Grant Abstracts	Appendix D
Graduate Student Thesis Abstract	Appendix E
Grant Proposal Abstracts	Appendix F

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

STUDY DESIGN

Appendix A



STUDY DESIGN - A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

Pre-test

Self-administered instruments at pre-surgical recruitment

Demographics

- Age
- Weight
- Height
- Race
- Co-morbidities
- Allergies

Physical

- Functional status
- Activity level
- ADLs
- ROM

Psychological

- Anxiety State

Quality of Life

- Fact-B subscales
- Physical well-being
- Social/family well-being
- Relationship with doctor
- Emotional well-being
- Functional well-being
- Additional concerns

Post-Operative

Weeks 1 and 2

Intervention

Experimental Group

- Nurse phone contact 1
- Nurse in-home visit 1
- Nurse phone contact 2
- Nurse in-home visit 2
- Conventional care

Non-Intervention

Control A Group

- Agency nursing care
- Conventional care

Control B Group

- Conventional care

Post-test

Telephone interview at 4 weeks post-surgery

Physical

- Functional status
- Activity level
- ADLs
- ROM
- Post-surgical self-care
- Preventive self-care education
- Sensation in surgical area
- Surgical Drain

Psychological

- Anxiety State

Quality of Life

- Fact-B subscales
- Physical well-being
- Social/family well-being
- Relationship with doctor
- Emotional well-being
- Functional well-being
- Additional concerns

Costs

- Complementary therapies
- Out-of-pocket for care
- Patient initiated health services
- Employment/financial changes

Chart Audit

4 month follow-up

Post-Protocol Events

- Seroma Formation
- Further Surgeries
- Axillary node dissection
- Lumpectomy
- Wide excision
- Mastectomy
- Double Mastectomy
- Prophylactic Mastectomy
- Other

Follow-up Data

- Cancer Stage
- Body Mass Index

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

GRANT PRODUCTIVITY REPORT
Appendix B

*A Subacute Care Intervention
for
Short-Stay Breast Cancer Surgery*

September 15, 1996 to September 14, 2000

Productivity Report

Funded by:

U. S. Army Medical Research
Materiel Command
Department of Defense

Principal Investigator:

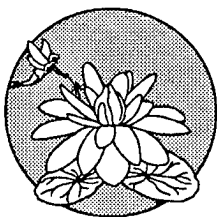
Gwen Wyatt, RN, PhD
Associate Professor, College of Nursing

Co-Principal Investigators:

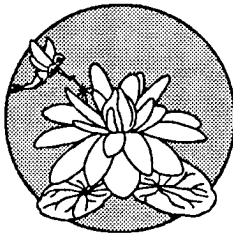
Barbara Given, PhD, RN, FAAN
Professor, College of Nursing
Institute of Managed Care
Director of Research

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Family Practice
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A New Beginning



Nursing Care for Breast Cancer Staff Productivity Report

Fall 1996 through Fall 1999

PUBLICATIONS

Wyatt, G.K., Friedman, L.L., Given, C.W., Given, B.A., & Beckrow, K.C. (1999). Complementary therapy use among older cancer patients. Cancer Practice, 7(3), 136-144.

Wyatt, G.K., Friedman, L.L., Given, C.W., & Given, B.A. (1999). A profile of bereaved caregivers following provision of terminal care. Journal of Palliative Care, 5(1), 13-25.

Wyatt, G.K. & Friedman, L.L. (1998). Physical and psychosocial outcomes of midlife and older women following surgery and adjuvant therapy for breast cancer. Oncology Nursing Forum, 25(4), 761-768.

Wyatt, G.K., Kurtz, M.E., Friedman, L.L., Given, B.A., & Given, C. W. (1997). Preliminary testing of the Long-Term Quality of Life (LTQL) Instrument for female cancer survivors. Journal of Nursing Measurement, 4(2), 153-170.

Wyatt, G.K. & Friedman, L.L. (1996). Development and testing of a quality of life model for long-term female cancer patients. Quality of Life Research, 5, 387-394.

Wyatt, G.K. & Friedman, L.L. (1996). Long-Term female cancer survivors: Quality of life issues and clinical implications. Cancer Nursing, 19(1), 1-7.

MANUSCRIPTS SUBMITTED

Wyatt, G.K., Ogle, K. & Given B.A. (under review). Hospice focus groups: Recommendations from the bereaved. Journal of Palliative Medicine.

REVIEWER

Wyatt, G.K. (1998-1999). Reviewer for Research in Nursing and Health. New York, NY: John Wiley and Sons Inc.

Reviewer, continued

Wyatt, G.K. (1997-1998). Reviewer for College of Nursing Research Initiation Grants (CONRIG), Michigan State University, East Lansing, MI.

Wyatt, G.K. (1996-1998). Reviewer for Sigma Theta Tau Alpha Psi Chapter, College of Nursing, Michigan State University, East Lansing, MI.

PRESENTATIONS

Beckrow, K.C., Wyatt G.K., Friedman, L.L., Given, C.W. & Given, B.A. (1999, May 13). Complementary Therapy Use Among Older Cancer Patients. Paper presentation for the 22nd Annual Michigan Family Practice Research Day Conference, Michigan State University, East Lansing, MI.

Rovoll, M.D. & Wyatt, G.K. (1999, May 13). The Challenges of Quality Assurance in Data Entry. Paper presentation for the 22nd Annual Michigan Family Practice Research Day Conference, Michigan State University, East Lansing, MI.

Beckrow, K.C., Wyatt, G.K., Given, C.W., & Given, B.A. (1999, April 20). A Conceptual Model for an In-Home Nursing Intervention following Short-Stay Surgery for Breast Cancer. Poster presentation for the Seventh Annual Greater Lansing Nursing Research Day, Ingham Regional Medical Center, Lansing, MI.

Wyatt, G.K., Friedman, L.L., Given, C.W., & Given, B.A. (1999, April 20). A Profile of Bereaved Caregivers following Provision of Terminal Care. Poster presentation for the Seventh Annual Greater Lansing Nursing Research Day, Ingham Regional Medical Center, Lansing, MI.

Wyatt, G.K. (1999, March 10). Guided Imagery Application in Health Care. Invited speaker for the Center for Health, Humanities, and Well-Being Seminar Series at Sparrow Health System, Lansing, MI.

Wyatt, G.K., Friedman, LL., Given, C.W., & Given, B.A. (1999, February 18-20). A Profile of Bereaved Caregivers Following Provision of Terminal Care. Poster presentation for the 11th MASCC International Symposium, "Supportive Care in Cancer," Nice, France.

Wyatt, G.K., Friedman, L.L., Given, C.W., Given, B.A., & Beckrow, K.C. (1999, February 20). Complementary Therapy Use Among Older Cancer Patients. Paper presentation for the 11th MASCC International Symposium, "Supportive Care in Cancer," Nice, France.

Friedman, L.L. & Wyatt, G.K. (1999, February 18-20). Physical and Psychosocial Outcomes Following Breast Cancer Surgery: Implications for Supportive Care. Poster presentation for the 11th MASCC International Symposium, "Supportive Care in Cancer," Nice, France.

Presentations, continued

Wyatt, G.K. (1998, November 20). Nurse Sensitive Outcomes for the Short-Stay Breast Cancer Patient. Paper presentation for Oncology Nursing Society, State-of-the-Knowledge Conference on Nurse Sensitive Outcomes, Downtown Hilton, Pittsburgh, PA.

Wyatt, G.K. (1998, November 17). Therapeutic Touch: Evidence and Practice. Invited Speaker Seminar sponsored by the Michigan Complementary and Alternative Research Center, School of Medicine, University of Michigan, Ann Arbor, MI.

Wyatt, G.K. & Beckrow, K.C. (1998, July and August). Organizers for 1998 Summer Research Series, with presentations by Cathy Bradley, PhD, MPA, on health costs, Frederick Tims, PhD, RMT-BC, on music therapy, Daniel Murman, MD, MS, on impaired cognition in cancer patients, Michigan State University, East Lansing, MI.

Wyatt, G.K., Beckrow, K.C., & Bloomfield, M. (1998, June 16). Breast Cancer Awareness. Presentation for Nursing Continuing Education Summer Tuesday Evening Series: Women's Health Issues. Michigan State University, East Lansing, MI.

Wyatt, G.K., Given, B.A., & Given, C.W. (1998, May 7-10). Bridging the Gap between Nursing Outcomes and the Research Process: One-Step Computerized Documentation and Direct Data Entry. Poster presentation for the Oncology Nursing Society 23rd Annual Congress — On Track to a Changing World, San Francisco, CA.

Bloomfield, M. & Wyatt, G.K. (1998, April 30). Post-Operative Seroma Formation Following Breast Cancer Surgery. Presentation for the 21st Annual Michigan Family Practice Research Day Conference, Michigan State University, East Lansing, MI.

Beckrow, K.C. & Wyatt, G.K. (1998, April 30). The Impact of an In-Home Nursing Intervention for Women Following Short-Stay Surgery for Breast Cancer. Presentation for the 21st Annual Michigan Family Practice Research Day Conference, Michigan State University, East Lansing, MI.

Bloomfield, M. & Wyatt, G.K. (1998, April 29). Post-Operative Seroma Formation Following Breast Cancer Surgery. Poster presentation for the Nursing Research Day, sponsored by The Greater Lansing Nursing Research Consortium, Lansing, MI.

Sprague, J. & Wyatt, G.K. (1998, April 27). Bridging the Gap Between Nursing Outcomes and the Research Process. Poster presentation for the Undergraduate Research Opportunity Program (UROP) 1997-98 Banquet, Michigan State University, East Lansing, MI.

Wyatt, G.K. (1998, April 27). UROP Mentor Experience. Invited speaker for the Undergraduate Research Opportunity Program (UROP) 1997-98 Banquet, Michigan State University, East Lansing, MI.

Presentations, continued

Bloomfield, M. & Wyatt, G.K. (1998, April 3-4). Post-Operative Seroma Formation Following Breast Cancer Surgery. Poster presentation for the Research Recognition Day sponsored by the Graduate School and Council of Graduate Students (COGS), East Lansing, MI.

Wyatt, G.K., Beckrow, K.C., & Rovoll, M.D. (1998, February). Breast Cancer Research. Study staff provided information about breast cancer and the Nursing Care for Breast Cancer Study to nursing students from the Florence Nightingale School of Nursing, London, England. Presentation held at Nursing Care for Breast Cancer Study office, B422 West Fee Hall, Michigan State University, East Lansing, MI.

Wyatt, G.K. (1998, February 17). Nursing Care for Breast Cancer Project. Speaker for the Research Seminar Series through the College of Nursing Research Center, Michigan State University, East Lansing, MI.

Wyatt, G.K., Given, B.A., & Given, C.W. (1997, October 31-November 4). A Subacute Care Intervention for Short-Stay Breast Cancer Surgery. Poster presentation at the Department of Defense Breast Cancer Research Program Conference — Era of Hope: A Multidisciplinary Report of DoD Progress, Washington, D.C.

Wyatt, G.K. (1997, October 21). Breast Cancer: Post-Surgical Care. Invited speaker for the 30th Anniversary Great Lakes Cancer Nursing Conference, sponsored by the American Cancer Society, Novi, MI.

Wyatt, G.K., Bloomfield, M. & Beckrow, K.C. (1997, June and July). Organizers for 1997 Summer Research Series, with presentations by Given, B., Pathak, D., Neumark, D., and Siegl, E.J., Michigan State University, East Lansing, MI.

Wyatt, G.K. (1997, May 3). Preliminary Testing of a Long-Term Quality of Life Instrument. Poster presentation for Oncology Nursing Society Congress, New Orleans, LA.

Wyatt, G.K. (1997, January). Physical and Psychosocial Needs of Midlife and Older Women Following Surgery and Adjuvant Therapy for Breast Cancer. Fourth National Conference on Cancer Nursing Research, Panama City, FL.

Wyatt, G.K. (1996, November). New DOD Funding for Breast Cancer Transition Care Research. College of Nursing, Research Center Seminar Series, East Lansing, MI.

ABSTRACTS SUBMITTED

Wyatt, G.K., Given, C.W., & Given, B.A. (Submitted 1999, August). Complementary Therapy for Chemotherapy Patients and their Family Caregivers. Submitted for poster presentation to the 25th Annual Congress of the Oncology Nursing Society to be held in San Antonio, TX, May 11-14, 2000.

Abstracts Submitted, continued

Wyatt, G.K., Given, C.W., Given, B.A., & Friedman, L.L. (Submitted 1999, August). A Profile of Bereaved Caregivers Following Provision of Terminal Care. Submitted for poster presentation to the 24th Annual Research Conference of the Midwest Nursing Research Society to be held in Dearborn, MI, March 31-April 3, 2000.

ABSTRACTS ACCEPTED

Beckrow, K.C., Wyatt, G.K., Given, C.W., Given, B.A., & Friedman, L.L. (1999, August). Complementary Therapy Use among Older Cancer Patients. Accepted for poster presentation to the American Cancer Society Great Lakes Cancer Nursing Conference to be held in Novi, MI, October 19-21, 1999.

Smania, M., Wyatt, G.K., Given, C.W., & Given, B.A. (1999, August). A Conceptual Model for an In-Home Nursing Intervention following Short-Stay Surgery for Breast Cancer. Accepted for poster presentation to the American Cancer Society Great Lakes Cancer Nursing Conference to be held in Novi, MI, October 19-21, 1999.

Wyatt, G.K., Friedman, L.L., Given, C.W., Given, B.A., & Beckrow, K.C. (1998). Complementary therapy use among older cancer patients. Accepted for poster presentation to the Midwest Nursing Research Society's (MNRS) 23rd Annual Research Conference to be held in Indianapolis, IN, April 9-12, 1999.

ABSTRACTS PUBLISHED

Beckrow, K.C., Wyatt, G.K., Friedman, L.L., Given, C.W., & Given, B.A. (1999, May). Complementary Therapy Use Among Older Cancer Patients. Michigan Family Practice Day. Published in Proceedings Book, p. 8.

Rovoll, M.D. & Wyatt, G.K. (1999, May). The Challenges of Quality Assurance in Data Entry. Michigan Family Practice Research Day. Published in Proceedings Book, p. 8.

Wyatt, G.K. & Given, B.A. (1999, February). Recommendations for pro-active hospice education: A perspective from the bereaved. 5th National Conference on Cancer Nursing Research sponsored by the Oncology Nursing Society, the American Cancer Society, and the Association of Pediatric Oncology Nurses. Published in Syllabus and Conference Guide, p. 211.

Wyatt, G.K., Friedman, L.L., Given, C.W., & Given, B.A. (1999, February). A Profile of Bereaved Caregivers following Provision of Terminal Care. 11th MASCC International Symposium "Supportive Care in Cancer." Published in the Supportive Care in Cancer Program, Talk Summaries, and Abstract Book, p. 185.

Abstracts Published, continued

Wyatt, G.K., Friedman, L.L., Given, C.W., Given, B.A., & Beckrow, K.C. (1999, February). Complementary Therapy Use Among Older Cancer Patients. 11th MASCC International Symposium "Supportive Care in Cancer." Published in Published in the Supportive Care in Cancer Program, Talk Summaries, and Abstract Book, p. 153.

Friedman, L.L. & Wyatt, G.K. (1999, February). Physical and Psychosocial Outcomes Following Breast Cancer Surgery: Implications for Supportive Care. 11th MASCC International Symposium "Supportive Care in Cancer." Published in the Supportive Care in Cancer Program, Talk Summaries, and Abstract Book, p. 186.

Wyatt, G.K., Given, B.A., & Given, C.W. (1998, November). Nurse-Sensitive Outcomes for the Short-Stay Breast Cancer Patient. Oncology Nursing Society's State-of-the Knowledge Conference on Nurse-Sensitive Outcomes. Published in Proceedings Book, p.35.

Wyatt, G.K., Given, B.A., & Given, C.W. (1998, May). Bridging the Gap Between Nursing Outcomes and the Research Process: One-Step Computerized Documentation and Direct Data Entry. Oncology Nursing Forum, 25(2), 347.

Bloomfield, M. & Wyatt, G.K. (1998, April). Post-Operative Seroma Formation Following Breast Cancer Surgery. Research Recognition Day sponsored by the MSU Graduate School and Council of Graduate Students (COGS). Published in Proceedings Book.

Bloomfield, M. & Wyatt, G.K. (1998, April). Seroma Formation Following Breast Cancer Surgery. Nursing Research Day sponsored by the Greater Lansing Nursing Research Consortium. Published in Proceedings Book.

Bloomfield, M. & Wyatt, G.K. (1998, April). Post-Operative Seroma Formation Following Breast Cancer Surgery. Michigan Family Practice Research Day. Published in Proceedings Book, p. 23.

Beckrow, K.C. & Wyatt, G.K. (1998, April). The Impact of an In-Home Nursing Intervention for Women Following Short-Stay Surgery for Breast Cancer. Michigan Family Practice Research Day. Published in Proceedings Book, p. 23.

Wyatt, G.K. (1997). Preliminary Testing of the Long-Term Quality of Life (LTQL) Instrument for Female Cancer Survivors. Oncology Nursing Forum, 24(2), 311.

Wyatt, G.K. (1997). A Subacute Care Intervention for Short-Stay Breast Cancer Surgery. Department of Defense Breast Cancer Research Program Conference — Era of Hope: A Multidisciplinary Reporting of DOD Progress. Published in Proceedings Book, 3, p. 1033.

Wyatt, G.K. (1997). Breast Cancer: Post-Surgical Care. 30th Anniversary Great Lakes Cancer Nursing Conference. Presentation outline published in Proceedings Book, p. 22.

Abstracts Published, continued

Wyatt, G.K. (1997). Physical and Psychosocial Needs of Midlife and Older Women Following Surgery and Adjuvant Therapy for Breast Cancer. Fourth National Conference on Cancer Nursing Research sponsored by the American Cancer Society. Published in Abstract Book, p. 90.

Wyatt, G.K. (1996). Quality of Life of Female Cancer Survivors. Supportive Care in Cancer, 4(3), 232.

Wyatt, G.K. (1996). Models for Assessing Quality of Life Among Female Cancer Survivors. Michigan Family Practice Research Day. Published in Proceedings Book.

GRANT PROPOSALS UNDER REVIEW

Wyatt, G.K., Collins, C., & Bradley, C. (1999). Improving Outcomes Through a Supportive Intervention: A Continuum of Holistic Care. Submitted to the Department of Defense. Submission date: July 28, 1999.

Wyatt, G.K., Given, B.A., & Given, C.W. (1999). Supportive Care for Women with Late Stage Breast Cancer. Submitted to the Center of Alternative Medicine (CAM) and the National Institutes of Health (NIH). Submission date: May 24, 1999.

GRANT FUNDING

Gift, A., Given, B. (8/99 to 7/02). End of life Care. Competitive Strategic Partnership Grants, Michigan State University. (Wyatt, G. K. collaborator). (3 year budget, \$500,000). Funded.

Paneth, N. (6/1/99 to 5/30/04). Training Clinical Researchers for Community Settings. National Institutes of Health, K-01 grant. (Wyatt, G.K. Mentor in clinical research). (5 year budget, \$200,000/year). Funded.

Given, C.W., Wyatt, G.K., & Given, B.A. (7/1/98-6/1/00). A Complementary Therapy Intervention for Supportive Care of Cancer Patients. Collaborative partnership between West Michigan Cancer Center, Michigan State University, and the Mary Margaret Walther Program (2 year budget \$297,293). Funded 7/98.

Wyatt, G.K. Research Support. Funded 1/1/98 by the Office of the Provost, Michigan State University (1 year budget \$2,100).

Wyatt, G.K. (Principal Investigator), Given, C., & Given, B. (Co-principal Investigators). (Submitted 9/13/95). A Subacute Care Intervention for Short-Stay Breast Cancer Surgery. Funded 9/15/96 by the Department of Defense, grant #DAMD17-96-1-6325 (4 year budget \$799,558).

GRANT REPORTS

Wyatt, G.K., Given, B.A., Given, C.W., & Beckrow, K.C. (1998, October). Report of 2nd year progress on the study "A Subacute Care Intervention for Short-Stay Breast Cancer Surgery". Submitted to the U.S. Army Medical Research and Materiel Command, Department of Defense.

Wyatt, G.K., Given, B.A., Given, C.W., & Beckrow, K.C. (1997, September). Report of 1st year progress on the study "A Subacute Care Intervention for Short-Stay Breast Cancer Surgery". Submitted to the U.S. Army Medical Research and Materiel Command, Department of Defense.

PROFESSIONAL PRESENTATIONS ATTENDED BY STAFF

Manfred Stommel, PhD, Michigan State University, College of Nursing (1998, June 15). Data Management. Patenge Room, East Fee Hall, Michigan State University, East Lansing, MI.

Rachel Remen, MD, University of California - San Francisco, School of Medicine (1998, April 21). In the service of life: Finding meaning and mystery in the practice of health care. Kellogg Center, Michigan State University, East Lansing, MI.

Steven Keller, PhD, University of New Jersey, School of Medicine (1998, March). The immune system: Minding the body and embodying the mind. Marriott, East Lansing, MI.

GRANT DEVELOPMENT MEETINGS

Wyatt, G.K. (1998, October 12). Attended the Walther Cancer Institute Annual Program, Indiana University, Indianapolis, IN.

STAFF AWARDS

Bloomfield, M. (1998, Spring). Awarded the Janice and Alton Granger Endowed Student Scholarship to use toward graduate studies at Michigan State University, College of Nursing, East Lansing, MI 48824.

MEDIA COVERAGE AND PRESS RELEASES

Wyatt, G.K. & Rovoll, M.D. (1998, November 30 & December 1). AIDS Awareness Day. Participated in ribbon tying ceremony to commemorate World AIDS Day. Channel 6 News, Lansing, MI.

Wyatt, G.K., Given, B.A., & Given, C.W. (1998, Fall). Care for the Caregivers. Article in Michigan State University newsletter "Research News", Michigan State University, East Lansing, MI.

Media Coverages and Press Releases, continued

Wyatt, G.K. (1998, August). Short-Stay Mastectomy Patients Don't Go Home Alone. Article in Michigan State University newsletter "Research News", East Lansing, MI.

Wyatt, G.K., Given, B.A., Given, C.W., & Pathak, D. (1998, June). Hospital to Home. Nursing Care for Breast Cancer Study featured on the Science Coalition Web site, "MSU Research: Discovering a World of Promise," Michigan State University, East Lansing, MI.

Wyatt, G.K. & Sprague, J. (1998, June). McNair/SROP Scholars. Publication highlighting the experiences of the Undergraduate and Scholars Research Programs. Offered through the Office of Supportive Services, Michigan State University, East Lansing, MI.

Wyatt, G.K. (1998, May). In Support of Therapeutic Touch (T.T.): A Rebuttal to the Article in the Journal of the American Medical Association (JAMA) that denounced T.T. Radio interview with Dennis Krolick for MSU News Hotline (Audio news feed-line/sound bites for 24 hour radio service. Available for broadcast by any radio station in U.S. or Canada). Contact number: 1-800-321-6397.

Wyatt, G.K. (1998, Spring). Short-Stay Mastectomy Patients Don't Go Home Alone. Article in Michigan State University newsletter "MSU Nursing", East Lansing, MI.

Wyatt, G.K. (1997, December 10). Short-Stay Mastectomy Patients Don't Go Home Alone. Press interview for news release through Michigan State University, Office of the Vice President for Research and Graduate Studies.

Wyatt, G.K. (1997, November). Breast Cancer Source Guide. Contributor to media release. Contact person: Tom Oswald, Media Communications Department, Michigan State University, East Lansing, MI.

Wyatt, G.K. (1997, October 28). Breast Cancer Awareness. Television interview with Elizabeth Woolly on "Meridian Magazine", Channel 21, HOM-TV, Okemos Cable Television, (aired November 24 - December 7, 1997).

Wyatt, G.K. (1997, October 1). MSU Tip Sheet. Contributor to media release. Contact person: Russ White, Media Communication Department, Michigan State University, East Lansing, MI.

Wyatt, G.K. (1997, July 17). Nursing Care Following Short-Stay Breast Cancer Surgery. Radio interview with D. Krolick, Broadcast/ Photo Division of University Relations, Michigan State University, for National 24 Hour Radio Information Hotline.

Wyatt, G.K. & Bloomfield, M. (1997, April 11). Television interview for WELG Channel 22 Cable Television. (Aired twice a day April 14 through April 20, 1997).

Media Coverage and Press Releases, continued

Wyatt, G.K. (1997, Spring/Summer). Recent publications (4) cited in the Cancer Center at Michigan State University (CCMSU) Newsletter, Michigan State University, East Lansing, MI.

Wyatt, G.K. (1997, March 25). Mammograms Urged at Age 40. Press interview for news release through Michigan State University, Division of University Relations.

Wyatt, G.K. (1997, March 10). Michigan State University Study to Help Women Diagnosed with Breast Cancer. Press interview for news release through Michigan State University, Division of University Relations.

Wyatt, G.K. (1997, February 18). Longer Hospital Stays Not Always the Answer. Press interview for news release through Michigan State University, Division of University Relations.

Wyatt, G.K. (1996, Fall). Investigator Focus. Feature article in CCMSU Newsletter, Michigan State University, East Lansing, MI.

POLICY CONTACTS AND INVOLVEMENT

Wyatt, G.K., Beckrow, K.C., & Bloomfield, M. (1998, February). Advanced Practice Nurse (APN) Prescriptive Authority and Senate Bill 104. Letter submitted to Senator Dianne Byrum requesting her support of SB 104, East Lansing, MI.

LAY PRESENTATIONS AND ARTICLES

Wyatt, G.K. (1998, November 17). Therapeutic touch: Evidence and practice. Brown Bag Seminar sponsored by the University of Michigan Complementary and Alternative Research Center, Ann Arbor, MI.

Wyatt, G.K. (1998, April 27). UROP Mentor Experience. Invited speaker for the Undergraduate Research Opportunity Program (UROP) 1997-98 Closing Banquet, Michigan State University, East Lansing, MI.

Wyatt, G.K., Beckrow, K.C., & Rovoll, M.D. (1998, February). Breast Cancer Research. Study staff provided information about breast cancer and the Nursing Care for Breast Cancer Study to nursing students from the Florence Nightingale School of Nursing located in London, England. Presentation held at Nursing Care for Breast Cancer Study office, B422 West Fee Hall, Michigan State University, East Lansing, MI

Wyatt, G.K., Bloomfield, M., & Rovoll, M.D. (1998, January 8). Health Professions Experience. Study staff provided a required experience for East Lansing High School chemistry class students in a health profession environment. Students spent an afternoon learning about the profession of nursing, breast cancer, and the goals of the Nursing Care for Breast Cancer study.

Lay Presentations and Articles, continued

Wyatt, G.K. (1996, November 19). The Breast Cancer Experience. Presentation for the Unitarian Universalist Church Women's Group, East Lansing, MI.

Wyatt, G.K. (1996, October). Sigma Theta Tau Alpha Psi Chapter Anniversary. Poster for the College of Nursing Homecoming Celebration, East Lansing, MI.

M.S.U. STUDENT MENTOR

Wyatt, G.K. (1998, January). Mentor for East Lansing High School students. The objective of the experience was to provide students with an opportunity to see what a professional career in nursing research involves.

Wyatt, G.K. (1997-1998). Sponsored freshman student, Jill Sprague, from the Undergraduate Research Opportunity Program (UROP). The objective of the experience was to help the student develop a basic understanding and appreciation for research.

Wyatt, G.K. (1998, February). Mentor for nursing students from the Florence Nightingale Institute during their visit to the MSU. College of Nursing. The objective of the experience was to provide the students with a brief overview of breast cancer nursing research in the United States.

Wyatt, G.K. (1996-Present). Mentor for graduate students working on grant. Experience provides opportunities to present research at professional conferences, develop writing skills by participating in manuscript development, and provide guidance in students' pursuit of research/professional careers.

Wyatt, G.K. (1996-Present). Mentor for undergraduate students working on grant. Experience provides opportunities to be involved in the research process and encourage professional development.

WEB SITE DEVELOPMENT

Wyatt, C., Beckrow, K.C., & Wyatt, G.K. (1998, May). Nursing Care for Breast Cancer Web Site Development. Site gives an overview of study including purpose and aims, study design, nursing protocol, instruments used, funding source, study members, participating surgeons, bibliography of study related articles, and breast cancer resources. (www.msu.edu/~nurse/bc)

DISSERTATION AND THESIS

Bloomfield, M. (1999). The effects of early versus delayed exercise on seroma formation and range of motion recovery in short-stay breast cancer surgery patients.

INTERNAL PUBLICATIONS

Quality Assurance Manual	July 1997
Nursing Guide to Paradox Computer Program	June 1997
Patient Charting Forms	June 1997
Recruiter Manual, Pontiac site	May 1997
Interview Manual	March 1997
Nurse Intervener Manual	February 1997
Recruiter Manual, Lansing site	January 1997

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A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

1998-1999 P.I. PUBLISHED JOURNAL ARTICLES **Appendix C**

Wyatt, G.K., Friedman, L.L., Given, C.W., Given, B.A., & Beckrow, K.C. (1999). Complementary therapy use among older cancer patients. Cancer Practice, 7(3), 136-144.

Wyatt, G.K., Friedman, L.L., Given, C.W., & Given B.A. (1999). A profile of bereaved caregivers following provision of terminal care. Journal of Palliative Care, 5(1), 13-25.

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Complementary Therapy Use Among Older Cancer Patients

PURPOSE: The purpose of this study was to assess the use of complementary therapies among older cancer patients, to report patterns of use, and to understand who is more likely to use complementary therapies.

DESCRIPTION OF STUDY: A survey was conducted of 699 older cancer patients at 4 weeks and 6 weeks into cancer treatment. All participants were 64 years of age or older, had received a diagnosis of breast, colorectal, prostate, or lung cancer, and were recruited from community cancer treatment centers throughout Michigan. Measures of interest included self-reported physical symptoms, depressive symptomatology, optimism, spirituality, and use of conventional and complementary health services.

RESULTS: Approximately 33% of older cancer patients reported using complementary therapies. These individuals were more likely to be women, to be breast cancer patients, and to have a higher level of education. The three most frequently used therapies were exercise, herbal therapy, and spiritual healing. Complementary therapy users were significantly more optimistic than nonusers. Also, there were significant differences between users and nonusers on types of physical symptoms experienced, but no differences on reported depressive symptomatology or spirituality.

CLINICAL IMPLICATIONS: Oncology providers need to be aware that one third of their older patients are likely to supplement conventional care with complementary therapies. Therefore, providers should be knowledgeable about the safety and efficacy, in particular, of various exercise programs, herbal and vitamin therapies, and spiritual healing. It would be beneficial to develop a system within cancer centers by which patients could easily report on their use of complementary therapies, allowing providers to work in partnership with their patients.

KEY TERMS: Cancer, Complementary therapy, Depression, Elderly, Optimism

As the formal healthcare system in the United States endures reorganization and restructuring, patients are "expressing concern about insensitive, limited, and hurried interactions in every setting, from small suburban hospitals to comprehensive health centers."¹ As a result, many people are turning to complementary therapies (CTs) as a way to supplement their healthcare needs.^{2,3} The Office of Alternative Medicine Panel on Definition and Description defines complementary therapies as "a broad domain of healing resources that encompasses all health systems, modalities, practices, and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period."⁴ Cassileth⁵ offered another, more specific, definition: "therapies used along with conventional medicine that are noninvasive, pleasant, stress-reducing, and can be used in states of sickness or health." CTs have been used for health promotion, and now increasing numbers of patients with acute or chronic illness are exploring their potential benefits.^{6,7} CTs are being incorporated as a

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way to alleviate symptoms associated with cancer treatment, in addition to providing much-needed psychosocial support and improving overall quality of life in patients with cancer.⁸

Literature Review

Current literature on CT use related to physical symptom management and a variety of psychosocial variables (ie, depressive symptomatology, optimism, and spirituality) were reviewed. Most variables have not been studied in relation to how or whether CTs may affect physical and psychosocial outcomes. A landmark outcome study conducted by Spiegel⁹ used CTs in patients with metastatic breast cancer. This study incorporated a variety of psychological interventions along with the CTs of imagery and self-hypnosis. The study included 86 participants, with 50 randomly assigned to the intervention group and 36 to the control group. The most significant outcome finding was survival time, with a mean of 36.6 months for intervention participants and 18.9 months for control subjects. Spiegel speculated that the possible mechanisms of action, as a result of the intervention, included changes in diet and exercise, better use and provision of healthcare, and positive effects on the sensitivity of the endocrine and immune systems. Such dramatic survival outcomes warrant further investigation into supportive CTs.

Complementary Therapy Use and Physical Outcomes

Redmond¹⁰ reported on the symptom experience of cancer patients undergoing treatment and the availability of supportive care, such as CTs. Conventional cancer treatments, such as chemotherapy, may cause many distressing symptoms and side effects, the most common being fatigue, nausea, and vomiting. Redmond concluded that although advances have been made in pharmacologic remedies, patients are finding that CTs can also provide much needed relief from these symptoms.

In working with chemotherapy outpatients, Post-White¹¹ randomly assigned participants to an experimental ($n = 22$) or control group. The intervention group, which practiced mental imagery for 4 months, demonstrated a significant improvement in perceived quality of life, emotional state, and disease state, as well as an improved immune function measure (lymphokine-activated killer cells). Similarly, Fawzy et al¹² found that support groups reduced mood disturbance in patients with malignant melanoma while also improving immune function.

Downer et al¹³ used mailed questionnaires and semi-structured interviews to assess 600 cancer patients for their use of CTs in addition to conventional treatments. Eighty-two percent of those using CTs reported high levels of satisfaction with their choices. Reported physical benefits included less difficulty in breathing, increased energy, and reduced nausea.

Complementary Therapy Use and Psychosocial Outcomes

Bindemann et al¹⁴ conducted a randomized, controlled study on relaxation training and ego-strengthening hypnosis as a coping resource for 80 men and women who were patients with cancer. Measures of depression, anxiety, and psychiatric morbidity were obtained at baseline, and at 6 and 12 weeks postintervention. Although intervention and control group scores were similar at baseline, intervention participants who were men reported significantly lower anxiety than those in the control group at 6 and 12 weeks. Intervention participants who were women had significantly lower scores than control subjects on all psychological measures at 6 and 12 weeks.

Fredette¹⁵ conducted a descriptive study of concerns and coping skills in 14 women who had survived breast cancer for a minimum of 5 years. The majority reported that the cancer experience had made them more aware of their vulnerability and had changed their views on life. Most had developed a "survivor personality" by using a variety of coping strategies, including visualization, spirituality, and diet to help them become successful survivors.

Halstead and Fernsler¹⁶ studied 128 long-term cancer survivors. Forty-eight percent reported adjustments in coping styles since their diagnosis. These new coping styles included relaxation techniques, positive affirmations, and spirituality.

These studies represent a beginning to the exploration of CTs, their use, and efficacy on various physical and psychosocial outcomes among cancer patients. Favorable outcomes range from improved survival time, to fewer physical symptoms, to improved immune function. Finally, many psychosocial indicators suggest reduced anxiety, improved coping styles, and enhanced quality of life.

While previous research has focused on specific types of cancer patients who may use CTs,¹⁷ it may also be useful to study CT use across patients with various types of cancer. It is well documented that middle-aged, well-educated, financially secure individuals are most likely to use CTs.^{6,7} However, because the vast majority of cancer patients are beyond middle age, it would be interesting to assess their use of CTs. The purpose of this paper is to report the patterns and extent of CT use by breast, lung, colorectal, and prostate cancer patients 64 years of age and older as well as the relationship of CT use to treatment-induced symptoms and psychosocial variables.

Methods

Design and Data Analysis

This nonexperimental, descriptive study was conducted with cancer patients who were receiving conventional medical treatment. Although the parent study for this project¹⁸ collected data during four waves, this paper reports data from wave 1. Informed consent was obtained at intake into the study, in accordance with the institutional review board where participants were recruited.

Descriptive analyses were performed on all variables. Reliability (alpha) coefficients for established, and original scales were computed for this sample when possible. Chi-square analyses and one-way analyses of variance were conducted to compare CT users to nonusers on a variety of measures. Correlations were performed on the study's primary variables to assess relationships between variables. Finally, a logistic regression analysis was performed in an attempt to predict CT use.

Sample

The sample of this study consisted of 699 cancer patients who were 64 years of age and older and who had received an initial diagnosis of prostate, lung, breast, or colorectal cancer. All patients with the specified cancer types, who were undergoing active cancer treatment at 24 community hospitals and affiliated cancer programs, were approached for participation in the study. The acceptance rate was approximately 73%, with men and older patients refusing participation more frequently. The stage of disease by site of cancer of the sample was within three percentage points of the distribution of cancer cases in the respective community cancer registries during the study (1993 to 1997). As requested by several community hospital institutional review boards, no demographic data were collected on those who declined participation in the study. However, site and stage at diagnosis of the participating sample was comparable to those reported by the 24 communities in which accrual occurred. Although the entire (parent) sample consisted of 1200 participants, 699 of these completed the CT questionnaires and interview.

Procedure

Data were gathered through self-administered questionnaires, telephone interviews, and chart audits. Intake occurred at the patient's first clinic visit after receiving a positive diagnosis for cancer, and demographic data were obtained from consenting participants. Data for this report were collected at 4 to 6 weeks after surgery or within 2 weeks of initiating adjuvant therapy (chemotherapy or radiation), via self-administered instruments and a 45- to 60-minute telephone interview. Participants mailed back the completed instruments that assessed CT use, depressive symptomatology, optimism, and spirituality. Telephone interviewers collected data related to symptom experience and conventional health service use. Interviewers were nurses or medical students with extensive interview training, including mock interviews, taped interviews, and quality assurance assessments on 10% of each interviewer's cases. Medical information, such as primary site and stage of cancer, was obtained through chart audits by trained nurses.

Measures

In addition to items assessing basic demographic information, the following six instruments were used: Physical

Symptom Experience, Centers for Epidemiologic Studies Depression Scale, Life Orientation Test Optimism Measure, Long-Term Quality of Life Spirituality Scale, Conventional Health Service Utilization, and Complementary Therapy Utilization.

Given et al¹⁹ developed the Physical Symptom Experience instrument, which asked participants how they had felt during the past 2 weeks, using a list of 37 symptoms. Included were questions such as, "Did you experience fatigue in the past two weeks?" answered with "yes" or "no" response choices, scored as 1 and 0, respectively. The established alpha was .90, and the sample alpha was .77.

The depression symptomatology instrument used in this study was the Centers for Epidemiologic Studies Depression Scale by Radloff and Locke.²⁰ This instrument included 20 items that assessed affective, behavioral, and cognitive features of an individual's depressive symptomatology. It included questions such as, "During the past month, how much of the time have you felt tearful?" Anchors were on a 4-point scale in which 0 was "rarely or none of the time," 1 was "some of the time," 2 was "most of the time," and 3 was "almost all of the time." Higher scores indicated greater depressive symptomatology. A composite score was computed by summing all scores for the 20 items, with a possible range of 0 to 60. The established alpha for this instrument was .92, and the sample alpha was .87.

Scheier and Carver²¹ developed the Life Orientation Test Optimism Measure, which contained eight items (with four positively worded and four negatively worded) to assess overall optimism. It included statements such as, "I always look on the bright side of things." Response choices were on a 4-point scale, in which 1 was "strongly agree," 2 was "agree," 3 was "disagree," and 4 was "strongly disagree." The established alpha, which was based on a 5-point scale, was .76. The sample alpha, based on a 4-point scale, was .82.

The Spirituality Scale, a 10-item subscale of the Long-Term Quality of Life instrument developed by Wyatt et al²² measured existential and philosophical views on life. It included statements such as, "I feel an inner direction that helps me make wise decisions." Respondents indicated their views about each statement on a 5-point scale in which 0 was "not at all," 1 was "a little," 2 was "a fair amount," 3 was "much," and 4 was "very much." The established alpha for this subscale was .87, and the sample alpha was .78.

Given and Given²³ developed the Conventional Health Service Utilization instrument. This instrument assessed the participants' use of five health services and included questions such as, "Have you used visiting nurses since you were diagnosed with cancer?" All items required a "yes" or "no" response and were scored as 1 and 0, respectively. The frequency of use and the cost of these services were also assessed and were recorded as write-in numerical variables. The sample alpha for the Conventional Health Service Utilization subscale was .29.

The Complementary Therapy Utilization instrument was developed by Wyatt²⁴ and asks which of 17 CTs a respondent had used. A question such as "Do you use herbal therapy?" was answered with "yes" or "no," and

scored 1 and 0, respectively. Frequency of CT use was also assessed and was recorded as a write-in numerical variable. The Complementary Therapy Utilization subscale had an alpha of .39 for this sample.

Results

Demographics

The majority of participants were white men, with a mean age of 72 years and at least a high school education. Prostate cancer was the most prevalent diagnosis, and overall, most participants had stage I or stage II cancer. Of the

total sample, 33.3% were CT users, and 23.9% used conventional health services. The mean number of different types of CTs used was 1.48, with a mean frequency of use of 10.84. CT users and nonusers were compared across all demographics. CT users were more likely than nonusers to be women and to have completed high school or beyond. In addition, a significantly greater proportion of CT users than nonusers had breast cancer versus other cancers. There were no other significant demographic differences between CT users and nonusers (Table 1).

Physical Symptom Experience

The most frequently reported symptoms by both CT users and nonusers included fatigue (66.0%), up at night to

Table 1. Patient Demographics: Complementary Therapy (CT) Use in Older Patients

	Total Sample		CT Users		Non-CT Users		P Value*
	n	%	n	%	n	%	
Gender							
Male	366	52.8	103	45.0	263	56.7	≤ .05
Female	327	47.2	126	55.0	201	43.3	
Ethnicity							
White	500	92.4	157	93.5	343	92.0	≤ .01
Other	41	7.6	11	6.5	30	8.0	
Education							
No formal education	2	0.3	1	0.5	1	0.2	≤ .01
Completed grade school	45	6.8	11	5.2	34	7.6	
Completed some high school	118	17.9	26	12.3	92	20.6	≤ .05
Completed high school	216	32.8	73	34.6	143	32.0	
Completed some college	162	24.6	48	22.7	114	25.5	≤ .05
Completed college	65	9.9	26	12.3	39	8.7	
Completed graduate college	50	7.6	26	12.3	24	5.4	≤ .05
Type of Cancer							
Prostate	206	30.2	65	28.5	141	31.1	≤ .05
Breast	198	29.1	83	36.4	115	25.4	
Lung	152	22.3	42	18.4	110	24.3	≤ .05
Colon	125	18.4	38	16.7	87	19.2	
Cancer Stage							
Stage 0	39	10.1	16	12.8	23	8.8	≤ .05
Stage I	122	31.7	48	38.4	74	28.5	
Stage II	130	33.8	40	32.0	90	34.6	≤ .05
Stage III	61	15.8	12	9.6	49	18.8	
Stage IV	33	8.6	9	7.2	24	9.2	≤ .05

	Total Sample			CT Users			Non-CT Users		
	M	SD	Range	M	SD	Range	M	SD	Range
Age (yrs)	72.21	5.04	65-98	72.17	5.40	65-93	72.23	4.86	64-98
CT Use	n	%		M	SD	Range			
Total sample using CTs	233	33.3		1.48	0.86	1-5			
CTs used				10.84	25.20	0-104			
CT treatments/participant									

*Based on chi-square analyses using Fisher's exact test (1-sided).

urinate (65.7%), and pain (47.6%). The mean number of symptoms reported for the total sample was 8. When comparing users and nonusers of CTs, six symptoms were reported by a significantly higher proportion of the users of CTs—pain, numbness/tingling/loss of feeling, leaking urine, mood changes, limitation in arm movement, and arm swelling. A significantly greater proportion of non-CT users reported symptoms of up at night to urinate, dry mouth, and diarrhea (Table 2).

Psychosocial Outcomes

All participants reported depressive symptomatology within the normal range for the general public.²⁵ There was no significant difference in depressive symptomatology between CT users and nonusers. When comparing the users of CTs to nonusers, users were significantly more optimistic. For the total group, participants reported relatively high spirituality, but there were no significant differences in spirituality scores between users and nonusers (Table 3).

Health Services

Conventional Health Services. The three most frequently reported services for the total sample included Visiting Nurse (18.2%), Social Worker (4.5%), and Nutritionist (3.8%). The highest number of treatments by service were Visiting Nurse ($M = 10.27$) and Counselor/Psychologist ($M = 8.79$) (M indicates mean). A significantly higher proportion of the CT users reported also having used conventional health services, as compared to the nonusers. Specifically, CT users were more likely to use visiting nurses and occupational therapy than non-CT users (Table 4). CT users also

reported using a significantly greater number of conventional health services than nonusers (Table 3).

Complementary Therapy Use. Descriptive analyses revealed that the three therapies used by the largest percentage of participants were exercise (16.7%), herbal therapy (12.5%), and spiritual healing (6.4%). The therapies with the highest number of treatments reported were other cancer therapy ($M = 14.40$), chiropractic manipulation ($M = 10.80$), spiritual healing ($M = 9.80$), and herbal therapy ($M = 9.29$) (Table 5).

Regression Analysis

A logistic regression analysis was performed to determine whether CT use could be predicted from the other data collected. Included in the analysis were the demographic variables (gender, age, education, ethnicity, cancer site, and cancer stage), depressive symptomatology, spirituality, optimism, physical symptoms, and conventional health service use. Three variables were specifically coded dichotomously: Education (completed high school or less vs completed some college or beyond), ethnicity (white vs "other"), and conventional health service use (users vs nonusers). Given statistically significant differences between CT users and nonusers in gender, education, type of cancer, optimism, and conventional service use, it was expected that these variables might constitute a model to predict CT use. However, the regression analysis found that only patient education level and conventional service use were predictive, with higher educational status and use of conventional health services predicting CT use.

The analysis was then rerun with only education and conventional health service use to preserve the sample size (model χ^2 ($df = 2$) = 14.86, $p \leq .001$). The odds ratio (Exp (B)) for education was 1.95, suggesting that participants

Table 2. Reported Frequency of Key Physical Symptoms in Complementary Therapy (CT) Users and Nonusers

Type of Symptom	Total Sample		CT Users		Non-CT Users		P Value*
	n	%	n	%	n	%	
Fatigue	438	66.0	149	69.0	289	64.5	
Up at night to urinate	436	65.7	131	60.6	305	68.1	$\leq .05$
Pain	316	47.6	113	52.3	203	45.3	$\leq .05$
Frequent urination	255	38.4	78	36.1	177	39.5	
Dry mouth	253	38.1	72	33.3	181	40.4	$\leq .05$
Trouble sleeping	241	36.3	79	36.6	162	36.2	
Weakness	240	36.1	87	40.3	153	34.2	
Weight loss	206	31.0	63	29.2	143	31.9	
Lack of sexual interest	197	29.7	63	29.2	134	29.9	
Diarrhea	153	23.0	40	18.5	113	25.2	$\leq .05$
Numb/tingling/loss of feeling	147	22.1	62	28.7	85	19.0	$\leq .01$
Leaking urine	136	20.5	53	24.5	83	18.5	$\leq .05$
Mood changes	136	20.5	62	28.7	74	16.5	$\leq .001$
Limitation arm movement	97	18.8	41	24.3	56	16.1	$\leq .05$
Arm swelling	29	5.6	14	8.3	15	4.3	$\leq .05$

*Chi-square analyses using Fisher's exact test (1-sided).

Table 3. Descriptive Data of Primary Variables

	Total Sample*			CT Users†			Non-CT Users‡			P Value§
	M	SD	Range	M	SD	Range	M	SD	Range	
Depressive symptomology **	11.00	7.71	0.0–42.0	11.03	7.72	0.0–38.0	10.98	7.71	0.0–42.0	
Optimism†***	3.01	0.41	2.0–4.0	3.06	0.43	2.0–4.0	2.99	0.40	2.0–4.0	≤ .05
Spirituality†††	3.07	0.60	0.9–4.0	3.13	0.56	0.9–4.0	3.04	0.61	1.2–4.0	
Physical symptoms **	8.18	4.45	0.0–21.0	8.38	4.70	0.0–21.0	8.08	4.32	0.0–20.0	
Conventional health services **§§	0.31	0.61	0.0–4.0	0.41	0.73	0.0–4.0	0.26	0.53	0.0–3.0	≤ .01
CTs **	0.50	0.86	0.0–5.0	1.49	0.86	1.0–5.0				

*n = 627–699.

†n = 204–233.

‡n = 423–462.

§Based on one-way analyses of variance between CT users and nonusers.

||Summed score.

†Mean score.

**On a scale of 0–60, with 0 indicating no depressive symptoms to 60, indicating severe depressive symptoms; less than 16 is considered normal for the general population.

**On a scale of 1–4, with 1 indicating low optimism to 4, indicating high optimism.

††On a scale of 0–4, with 0 indicating low spirituality to 4, indicating high spirituality.

‡‡On a scale of 0–37, with the score indicating the number of symptoms reported.

§§On a scale of 0–5, with the score indicating the number of services used.

||On a scale of 0–9, with the score indicating the number of therapies used.

who had some college or beyond were almost two times as likely to use CTs. Similarly, participants who used one or more conventional health services were about one and a half times as likely to also use CTs (Exp (B) = 1.57).

Correlational Analyses

Most of the variables measured were significantly inter-correlated. Significant correlations included: depressive symptomatology was positively correlated with physical symptoms and conventional health services, and negatively correlated with optimism and spirituality. Optimism was positively correlated with spirituality and negatively associated with physical symptoms. The presence of physical symptoms was positively correlated with conventional health services and CT use. Finally, the use of conventional health services was positively correlated with CT use (Table 6).

Discussion

Through various data analyses, the patterns of use of complementary therapies by older cancer patients, the

types of therapies most commonly used, and the frequency of use of various therapies were evaluated. This information can provide critical information for the development of practice guidelines.

Demographically, the CT users were significantly better educated than the nonusers, which is consistent with other surveys.^{6,7,17,26} Significantly more women were represented among the users of CTs, and breast cancer participants were the highest CT users among the four types of cancer patients surveyed. Because all breast cancer patients were women, the higher frequency of CT use among breast cancer patients may be solely a reflection of the patients' gender. It is not surprising that women were more likely to seek assistance with CTs, given the higher social acceptability for women than men to seek help.²⁷ Further, Bindemann et al¹⁴ found that women received more psychological benefits from CTs compared with their counterparts who were men. Women and better educated individuals may also be more open to nontraditional treatments. However, of the demographic variables, only education was actually predictive of CT use in this sample. It was most interesting to note that a higher percentage of the total sample used CTs than conventional health services. Although CTs generally incur

Table 4. Conventional Health Service Use: Percent Using Services and Mean Number of Visits

	Total Sample				CT Users				Non-CT Users				P Value*
	%	M	SD	Range	%	M	SD	Range	%	M	SD	Range	
Visiting nurse	18.2	10.27	10.21	1–60	23.5	11.23	10.48	3–6	15.6	9.55	10.02	1–60	≤ .01
Social worker	4.5	1.79	1.13	1–5	5.4	1.45	0.82	1–3	4.0	2.00	1.27	1–5	
Nutritionist	3.8	1.79	3.46	1–18	5.4	2.64	5.10	1–18	3.1	1.08	0.28	1–2	
Counselor/psychologist	2.2	8.79	5.49	1–15	2.5	9.00	4.95	3–15	2.1	8.67	6.06	1–15	
Occupational therapist	1.9	5.08	3.73	1–14	4.4	5.33	4.09	2–14	0.7	4.33	2.89	1–6	≤ .01
Overall use of services	23.9				29.4				21.3				≤ .05

*Based on chi-square analyses using Fisher's exact test (1-sided).

Table 5. *Top Complementary Therapies Used*

	% of Total Sample	M	SD	Range
Exercise program	16.7	8.33	6.94	3-30
Herbal therapy	12.5	9.29	15.18	1-56
Spiritual healing	6.4	9.80	11.17	1-33
Other cancer therapy	2.9	14.40	9.26	3-25
Massage	2.7	6.00	3.46	3-11
Chiropractic manipulation	2.4	10.80	6.61	3-20
Lifestyle diet	2.2	6.00	4.24	3-9
Relaxation/imagery/yoga	1.9	*	*	*
Audio or video tapes	1.4	2.00	1.41	1-3

*Missing data

out-of-pocket costs, participants were still more likely to use CTs than conventional services, which are often covered by insurance.²⁶

Many of the physical symptoms reported by significantly more of the CT users can be attributed to breast cancer, eg, limitation in arm movement and arm swelling. This finding is consistent with the fact that breast cancer patients were more likely to use CTs than other patients. Downer et al¹³ found that CTs were useful in relief of physical symptoms in cancer patients. It is possible that breast cancer patients could use exercise, herbs/vitamins, and spiritual healing to address their physical symptoms. Both Fredette¹⁵ and Halstead and Fernsler¹⁶ reported spirituality, in particular, as an effective coping strategy among cancer patients. Finally, physical symptoms were positively correlated with both conventional services and CTs, suggesting that use of both types of services might have reflected a general need for symptom relief.

In general, the users of CTs reported equal and sub-clinical depressive symptomatology and comparable degrees of spirituality when compared to the nonusers of CTs. The CT users were significantly more optimistic than participants who did not use CTs, although optimism did not actually predict CT use. It may be that respondents who were more optimistic about the future were also more likely to actively participate in their own healthcare by using CTs. Downer et al¹³ also found higher optimism among cancer patients who were CT users. The greater optimism

may provide the emotional energy needed to explore additional resources such as CTs, when confronted with a diagnosis as serious as cancer. Participants' incorporation of CTs may also represent different coping styles or levels of coping, as compared to their less optimistic counterparts who did not use CTs. The CT coping style may be indicative of what Fredette¹⁵ referred to as "the survivor personality." However, it is also possible that the significant difference in optimism can be attributed to a large sample size and may not truly reflect a clinically significant difference.

The most frequently used conventional health service, both in number of participants using the service and frequency of use, was visiting nurse care. This finding may reflect providers' current mindset that physical care, which is the primary service of visiting nurses, is the most beneficial or needed service for cancer patients.¹ The service with the second highest mean number of visits was that of a counselor/psychologist, and social work services reflected the third highest mean number of visits. Both the frequent use of counseling and the high number of participants seeing a social worker point to a prominent use of psychological services in general. This finding is consistent with previous studies that reported positive outcomes from psychosocial and complementary interventions.^{11,12,14,15} It would be interesting to know whether use of these emotionally supportive services were based upon self-referrals or provider referrals.

The most commonly used CTs were exercise, herbs and vitamins, and spiritual healing. These therapies may represent areas for provider education. Bauer²⁸ confirmed that accurate and scientifically based information on CTs can help providers feel more confident about the efficacy of CTs for patients. In addition, a fairly high number of participants reported use in the general category entitled *other cancer therapies*. This finding suggests there is still a "black box phenomena" that needs to be explored. Either participants used CTs that were not part of the forced-choice list or they did not wish to disclose the specific therapy they used. These possibilities raise the issue of how healthcare providers can more openly assess the use of CTs and, therefore, participate in planning safe, effective selections that truly complement conventional care.

In general, the number of participants using CTs and conventional health services was comparable, although CT use was somewhat higher than conventional health service use. In addition, CT users were more likely to also report

Table 6. *Correlations Between Primary Variables*

	Depressive Symptomatology	Optimism	Spirituality	Physical Symptoms	Conventional Health Services
Optimism	-.457*				
Spirituality	-.148*	.273*			
Physical symptoms	.492*	-.211*	-.030		
Conventional health services	.100*	-.055	.017	.123*	
Complementary therapies	.036	.057	.071	.098†	.084†

* $P \leq .01$ (2-tailed).† $P \leq .05$ (2-tailed).

use of conventional services, suggesting that use of CTs and conventional services may reflect help-seeking behavior or a willingness to seek assistance in coping with cancer.¹³

Limitations and Future Research

Although the total sample was large, there were often inadequate numbers of participants responding to the items on the CT measure to conduct statistical analyses beyond descriptive patterns. This limited response rate may be related to the age of the sample, which was considerably older than the mean age reported by other surveys.^{6,7,17,26} Perhaps a better method for obtaining data from this more mature sample would be the use of open-ended, face-to-face interviews. This more open approach may have improved the response rates by allowing for the exploration of cost data, satisfaction with CTs, and the reasons for using various CTs, eg, for specific symptom management. The addition of other psychosocial factors, such as anxiety or personality variables, including coping styles, would also be interesting to relate to CT use. In future research, perhaps a glossary of terms for CTs could assure a more consistent interpretation of each therapy, which would increase the reliability and validity of the CT measure. Further, it is unclear as to what was included in the "other therapies" category. Conducting focus groups with patients could help reveal what additional categories should be added to better assess the range of therapies likely to be used.

Other research methods might also produce more conclusive results. A controlled, clinical trial could assess the actual effects of CT use on symptoms and psychosocial outcomes, and compare them to outcomes from conventional health services. Finally, this research could be expanded to study CT use and its effects in other patient or community samples.

Clinical Implications

Oncology providers can benefit from being aware that up to 33% of their older patients may be using CTs to supplement their cancer treatment. This information can alert providers to assess appropriate community resources for safety and efficacy.²⁹⁻³¹ A directory of screened providers could be available in office waiting rooms. It will be important for providers to begin to include an assessment of each patient's use of CTs so there can be coordination with conventional care. By assessing CT use, the oncology provider can help guide and monitor the benefits and contraindications of various CTs.³² Eventually, oncology centers may wish to develop their own amenities menu of CTs provided within the clinic.³³ This could help to assure the quality of the CTs and to provide increased revenue, as patients are clearly willing to spend out-of-pocket for CTs.²⁶

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A Profile of Bereaved Caregivers Following Provision of Terminal Care

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Abstract / Caregivers are often overwhelmed by the strain of terminal caregiving. We wished to better understand the needs of terminal caregivers and to supply a basis for tailoring interventions to them during caregiving and early bereavement. This report provides a profile of 124 bereaved caregivers interviewed within three months of their patient's death. Three quarters were female and married to the patient. Four major areas were assessed: psycho-spiritual, personal-social, health status, and financial status. Caregivers reported higher than average depressive symptomatology (mean CES-D = 17.6), moderate levels of positive outlook, low negative reactions to caring, and relatively high levels of spirituality. Caregivers were highly involved in their patient's activities of daily living, providing an average of 10.8 hours/day of direct care and 8.9 hours/day of companionship. Caregivers reported low utilization of health services and relatively high personal health status. 45% of the sample reported lower income since the patient's death and 44% reported out-of-pocket expenses not covered by insurance. Suggestions for interventions that target emotional, physical, and financial concerns are discussed.

Résumé / Les soignants sont souvent écrasés par le fardeau des soins aux malades en phase terminale. Notre objectif était d'avoir une meilleure compréhension des besoins de ces soignants afin d'adopter nos modèles d'interventions auprès d'eux durant la phase terminale des soins et au début de la période de deuil. Ce rapport établit le profil de 124 soignants en deuil interviewés dans les 3 mois suivant la mort de leur patient. Des répondants, les trois quarts étaient des femmes mariées au patient. Les quatre aspects majeurs qui ont été évalués sont les suivants : psycho-spirituel, personnel-social, état de santé, et état financier. On a dénoté chez les soignants une symptomatologie dépressive plus élevée que la moyenne de la population (CES-D = 17.6), une attitude positive de niveau moyen, très peu de réactions négatives face aux soins à donner, et un très haut niveau de spiritualité. Les soignants étaient très occupés dans des activités journalières auprès de patients : 10.8 heures par jour étant consacrées aux soins de santé et 8.9 heures par jour à tenir compagnie au malade. Les soignants ont eu très peu besoin des services de santé pour eux-mêmes et la

qualité de leur état de santé était relativement élevée. 45 % des répondants ont rapporté que leurs revenus étaient moindres depuis la mort du conjoint et 44 % ont répondu qu'ils avaient dû faire face à des dépenses qui n'étaient pas couvertes par les assurances. Les auteurs suggèrent des approches d'interventions portant sur les aspects émotionnels, physiques et financiers.

INTRODUCTION

It is well documented that providing supportive care during the diagnosis and treatment of cancer may affect the mental health and stress level of the caregiver, who is often a family member (1-8). However, the terminal phase of care is seldom addressed in relation to the physical and economic outcomes of caregiving. In this time of health care reform, when more and more cancer care is shifting to the home, family caregivers are becoming involved in all phases of care throughout the cancer trajectory, including death. With increasing regularity, caregivers are required to put their own lives on hold to become involved with the needs of their dying loved one. Caregivers sacrifice their personal time and often their professional time too, frequently taking leaves from employment (9). As they become more involved in the provision of care, caregivers often feel isolated and ill-prepared to take on this new role (10,11). Caregivers are forced to shift their priorities and sometimes dramatically change their life plans due to the lack of certainty in regard to how long the patient will live (12).

The caregiver for the dying patient is now often a family member, and although caregivers do their best, there may be ways health professionals can better support the caregiver through the burdens of caregiving in order to improve caregiver outcomes during the early bereavement phase (13,14). It is important to examine the needs of the in-home caregivers as they resolve "who they are" after the death of their

patient, and to better understand the potential escalation of physical, emotional, and financial needs due to involvement in the terminal care.

LITERATURE REVIEW

Bereavement is a reaction to the death of a loved one. As a part of this reaction to loss, some grieving individuals experience symptoms characteristic of a major depressive episode (e.g. feelings of sadness and associated symptoms such as insomnia, poor appetite, and weight loss). The duration and expression of "normal" bereavement vary considerably among different cultural groups. An individual may be diagnosed as clinically depressed if intense symptoms are still present two months after the loss (15). Key areas in the bereavement and caregiver literature focus upon the burden of care for the caregiver, needs of the caregiver, and caregiver outcomes.

Spousal Attachment Loss and Conjugal Bereavement Related to Burdens of Care

The spousal and conjugal literature are primarily limited to care provided within marital relationships (16). Beck-Friis and Strang (10) investigated next of kin's satisfaction with professional home care during terminal care for a loved one and stated that "terminal care imposed a strain on the family — the carers — almost beyond description". These investigators suggested that health providers take a family genogram as an individual begins the caregiver role, to identify who may be most likely to need additional professional supportive care. In related research, attachment loss was found to be strongest in conjugal bereavement and contributed to more long-lasting depressive symptoms than when bereavement was due to the death of a child or parent (17).

Houts and colleagues (18) examined predictors of grief among 112 spouses of deceased cancer patients. Spouses who reported a high degree of emotional distress following the death tended to be younger, lived alone, said they had been upset just before the death, had avoided thinking about the possibility of their spouse's death, and reported that the patient had died at home. Stetz (19) explored the demands experienced by 65 spouse caregivers of terminally ill cancer patients. Based on an open-ended questionnaire, the demands most frequently reported were managing physical care and "standing by" watching the slow deterioration of the ill spouse.

Mor, Greer, and Kastenbaum (20) found that the primary caregiver fared significantly better when the patient was in a hospital-based hospice rather than at home in terms of emotional stress, feelings of burden, and satisfaction with patient

care. In contrast, Hays (21) found that it was when the patient required a period of institutionalization for symptom control prior to death that the caregiver experienced more anxiety and fatigue.

Although these studies add pieces to the puzzle of spousal caregiver outcomes, none present a composite profile of the bereaved caregiver. In addition, most of these studies examined psychological outcomes after bereavement but did not address financial, social, or physical sequelae.

General Needs of Caregivers

Several researchers have examined the experiences and unmet needs of caregivers of terminally ill patients. Houts, Yasko, and Harvey (22) found that the most frequently reported caregiver needs were for help with activities of daily living (ADLs). Mor, Guadagnoli, and Wool (23) reviewed 12 studies that investigated caregiver needs. These needs constituted concrete services such as personal care and instrumental activities of daily living (e.g. shopping, cooking, and cleaning). Other investigators offer further evidence that caregivers experience demands related to the practical tasks of daily living and provision of physical care (24,25). Hull (24) in particular studied 14 family members through semi-structured interviews and found that physical deterioration of their relative's condition brought about dependence on caregivers for very basic and personal ADLs.

Family caregivers identified three general sources of stress: patient symptoms, interactions with others, and concerns for themselves. For many families, the most distressing patient symptoms were those related to changes in their relative's mental status. Hull (24) suggested that by helping families examine realistic expectations for caregiving, feelings of guilt could be minimized and a healthier, more positive perception of their caregiving could be fostered. Jones, Hansford, and Fiske (11) also found that difficulties in coping with the patient's symptoms were a cause of distress to some caregivers. In addition, of the 207 carers of deceased cancer patients studied, most caregivers developed their own stress-related symptoms during the terminal phase. However, caregiver symptoms were not related to the degree of severity of patient symptoms and were not assessed post-bereavement.

Blank et al. (26) investigated perceived home care needs of eight cancer outpatients and their caregivers. Stressors identified by the caregivers included coping with the added responsibilities related to patient care, the fear of being alone, guilt, and limited knowledge regarding the pa-

tient's situation. These authors suggested that caregiver needs may include additional support with the patient's physical care, increased caregiver education, and psychological support in dealing with fear and guilt.

These studies point to the complexities of terminal caregiving and the stress placed on caregivers, but in most instances, they do not provide a bereavement assessment to determine the long-lasting effects of caregiving. Such an assessment of the caregiver after the patient's death would be useful to guide possible interventions for caregivers.

Factors Contributing to Caregiver Outcomes

Miller, McFall, and Montgomery (2) investigated caregiver involvement as related to caregiver burden. They interviewed 940 spouse and adult children caregivers who provided care for an elderly (age 65 or older) family member. Results indicated that the level of caregiver involvement in physical and household care influenced the caregiver's perceived stress and dimensions of burden. Therefore, the authors recommended interventions that target the caregivers' task involvement, such as utilizing homemaker or personal care services. Further, assistance with physical and household tasks relieved caregiver burden more directly than support groups that provided emotional and cognitive support. Although this study addressed caregiver involvement, it did not follow through to caregiver outcomes during the bereavement period.

In another study, Bass and Bowman (13) examined the relationship between care-related strain and the difficulty adjusting to the impaired relative's death. Panel data from spouse and adult-child caregivers collected before and after the death suggested that individuals who appraised caregiving as more difficult, and those who reported more negative caregiving consequences for the family, experienced bereavement as more difficult and reported greater bereavement strain for the family.

Norris and Murrell (27) found that older adults have difficulty maintaining their own health while caring for the needs of terminally ill relatives. Bereavement did have an effect on certain older adults, but the impact came before, rather than after, the death, and as a result of their higher family stress rather than the death itself. This study appears to yield further evidence that the general experience of providing care to loved ones is a distressing and physically taxing experience for older adults.

Given and colleagues (14) reported that patients' symptom distress, immobility, and de-

pendencies in ADLs were directly related to depression and to disruption of the caregivers' daily schedule. The caregiver's level of optimism was an important predictor of variations in caregiver depression, the perceived impact of caregiving on health, and, to a lesser degree, the impact on a caregiver's daily schedule. These results suggest that such personal attributes as optimism may play an important role in determining how a family member is likely to react to the imposition of providing care in the home.

Several other investigators have examined predictors of depression and health consequences among recently bereaved caregivers. Mor, McHorney, and Sherwood (28) analyzed the National Hospice Study bereavement interview data regarding the rate of medical care use and short-term secondary morbidity. The authors found that previous health problems and having been married to the deceased were consistently the strongest predictors of health care use and psychological and physical morbidity.

In another study of the same hospice data, McHorney and Mor (29) tested the determinants of clinical depression after bereavement in a large sample of caregivers. Results showed that consanguinity, patient age, poor prior physical and mental health, family tension, and survivor dissatisfaction with caretaking abilities during the terminal phase were the most important determinants of risk of depression after the death. Among spouses of deceased patients, bereavement depression was significantly associated with poor prior physical and mental health and dissatisfaction with caretaking abilities.

Many of these studies addressed the caregiver experience and pointed to specific variables that contribute to caregiver outcomes. However, they have not provided a comprehensive profile of the bereaved caregiver, including emotional, physical, spiritual, social, financial, and employment outcomes.

The bulk of the literature on terminal caregiving has focused to date on assessing and meeting patient needs at the end of life (19,24,25), but now, with the shifting of provision of care to the home, bereaved caregiver outcomes must become a new focus for the health professional. For this reason we profiled the bereaved caregiver three months after the death of the patient. The major concepts reported are the *psycho-spiritual profile*, the *personal-social profile*, *health status*, and the *financial adjustments* of the bereaved caregiver. This information may provide health professionals with valuable data on how to support the caregiver during the dying process and into early bereavement, so that he/

Table 1 / CAREGIVER DEMOGRAPHICS (n=124)

	Mean	SD	Range
Age in years at start of study	56.8	10.5	26-78
Years living with patient	30.8	15.9	0.08-53.8
	number	%	
Relationship to Patient			
Spouse	97	78.2%	
Daughter/son	15	12.1%	
Daughter-in-law	4	3.2%	
Sibling	2	1.6%	
Sib-in-law	1	0.8%	
Parent	2	1.6%	
Other	3	2.5%	
Total	124	100%	
Gender			
Female	93	75%	
Male	31	25%	
Total	124	100%	
Living with Patient	114	91.9%	
Education			
Grade school or less	4	3.2%	
Some high school	17	13.7%	
High school graduate	44	35.5%	
Some college	36	29.0%	
College graduate	12	9.7%	
Graduate/professor degree	10	8.1%	
Unknown	1	0.8%	
Total	124	100%	

Table 2 / PATIENT DEMOGRAPHICS (n=124)

	Mean	SD	Range
Age in years at start of study	62.2	11.0	24-82
Days of hospitalization immediately prior to death (n=55)	14.4	20.2	0-100
	number	%	
Type of Cancer			
Lung	40	32.3%	
Breast	17	13.7%	
Colon	17	13.7%	
Gastrointestinal	11	8.9%	
Lymphoma	10	8.1%	
Gynecological	6	4.8%	
Prostate	6	4.8%	
Head/neck	3	2.4%	
Other	14	11.3%	
Total	124	100%	
Gender			
Male	77	62.1%	
Female	47	37.9%	
Total	124	100%	
Setting of Death			
Home	67	54.0%	
Hospital	51	41.1%	
Nursing home	4	3.2%	
Other	1	0.8%	
Unknown	1	0.8%	
Total	124	100%	
Received Hospice Care	54	43.5%	

she can maintain the role as primary caregiver and not subsequently become a patient.

SAMPLE AND PROCEDURES

The original study upon which this paper is based used a convenience sample of patient/caregiver dyads from three community cancer centres in Michigan (30,31). The eligibility criteria for entry into the study were as follows: adult patients who were undergoing some form of initial treatment beyond palliation for a new diagnosis of cancer. Study participants were recruited at their first clinic appointment for treatment of their cancer. Each patient was asked to identify his/her primary caregiver, which was later confirmed by the named caregiver. Caregiver-patient dyads interested in participation completed and returned a self-addressed stamped postcard to the research centre. Over 80% of those caregivers who indicated an interest in the project returned cards and were then contacted by the research staff to determine eligibility and to explain conditions for participation.

The sample for this paper consisted of a subsample of 124 caregivers representing the caregivers of all patients who died during the course of the study. Tables 1 and 2 present sociodemographic characteristics of the caregivers and cancer-related information on their patients.

Data were gathered via three methods: telephone interview, self-administered questionnaires, and medical records of the patient. At the point of intake, a self-administered questionnaire was given to participants and they were instructed to return the questionnaire in a self-addressed stamped envelope. After the initial baseline data at intake, information was obtained from both the patient and caregiver six weeks after recruitment, via a telephone interview lasting approximately 45 to 60 minutes. The patient and caregiver were interviewed individually and were asked different structured, close-ended questions. The interview was followed up with a mailed, self-administered questionnaire packet for the patient and the caregiver. Follow-up interviews continued at 12, 24, and 52 weeks, as long as the patient lived. For the 124 patients who died during the study, a bereavement telephone interview was conducted with the caregiver approximately three months after the patient's death.

The interviewers were nurses or medical students who were provided with intensive training. Interviewer training included: (a) mock interviews, (b) taped interviews, and (c) quality assurance assessments conducted on 10% of the interviews, to ensure that the research protocol was followed.

MEASURES

Caregiver data collected three months after the patient's death included:

- *psycho-spiritual variables*: caregiver depressive symptomatology, positive outlook, negative reactions, and spirituality
- *personal-social variables*: caregiver involvement in care, activities since the death, burden of caregiving, and satisfaction with support from others during caregiving
- *caregiver health status variables*: health service utilization and health status of the caregiver
- *financial status variables*: income/expenditures and employment

The majority of these instruments were developed specifically for this study; therefore, reliabilities will be reported based on this sample wherever applicable (Table 3).

Instruments Used to Measure the Bereaved Caregivers' Psycho-Spiritual Profile

Depressive Symptomatology. Caregiver depressive symptomatology was measured by the Center for Epidemiologic Studies Depression Scale (CES-D) (32). This is an established instrument ($\alpha=0.85$ among the general population) used for screening persons for symptomatology related to depression (33). The CES-D consists of 20 items, with each item scored on a scale of 0 to

Table 3 / INSTRUMENTS USED TO DESCRIBE THE BEREAVED CAREGIVER

	Time Period	Number of Items	Sample Item	Scale Range	Alpha
Psycho-Spiritual Profile					
Depressive symptomatology	During 3rd month since death	20	Have you felt tearful?	0 (rarely or none of the time) to 3 (almost all of the time)	0.92
Positive outlook	During 3rd month since death	10	The future looks hopeful and promising.	1 (rarely or none) to 4 (almost all the time)	0.94
Negative reactions	3 months since death	10	Did you get angry with the person for whom you were providing care?	1 (very little) to 4 (a great deal)	0.81
Spirituality	3 months since death	11	I accept the mysteries of life and death.	1 (never or rarely) to 4 (always or almost always)	0.85
Personal-Social Profile					
Involvement in care	During last 4 weeks of patient's life	28	Did you assist with dressing the patient?	1 (yes), 2 (no)	0.74
Burden of care	3 months since death	38	I wish the family had depended less on me to care for the patient	1 (strongly agree) to 5 (strongly disagree)	0.94
Satisfaction with support from others	During terminal care and 3 months since death	4	Overall, how satisfied were you with the assistance you received from your family to care for your relative?	1 (very dissatisfied) to 4 (very satisfied)	0.81
Social activities	Before death and 3 months since death	9	Since the death of your relative how has the frequency with which you have friends over to your home changed?	1 (less than before death) 2 (about the same) 3 (more than before death)	0.74
Health Status Profile					
Health service utilization	3 months since death	13	In the past 3 months, have you seen a doctor?	1 (yes), 2 (no)	0.50
Health status	3 months since death	6	How would you rate your overall physical health at the present time?	Choices varied from 2 to 5	0.73
Financial Status Profile					
Income/Expenditures	3 months since death	68	Since your relative's death, do you have income from social security? In order to meet expenses related to the death of your relative, was it necessary for you to utilize life insurance benefits?	yes/no	N/A
Employment	3 months since death	11	Did caregiving for your relative prevent you from looking for a job?	yes/no	N/A

3. The higher the score, the greater the depressive symptomatology. A composite score was computed by summing the scores for the 20 items, with a possible range of 0 to 60. The alpha reliability of this instrument in this sample was 0.92.

Positive Outlook. An assessment of caregivers' outlook or disposition during the preceding month was conducted using a 10-item instrument with all items worded in a positive format, e.g. "The future looks hopeful and promising." The individual items were scored on a scale of 1 to 4, in which 1 indicated "rarely or none of the time", and 4 indicated "almost all of the time".

A composite score was computed as the average of item scores; therefore, the higher the score, the more positive the outlook. The alpha for this sample was 0.94.

Negative reactions. This instrument was composed of 10 items questioning feelings experienced during the terminal phase of caregiving that created negative emotions for the caregiver, such as, "Did you get angry with the person for whom you were providing care?" These items were on a 4-point scale in which 1 was "very little", 2 "somewhat", 3 "quite a bit", and 4 "a great deal". A higher score was equated with greater negative feelings. The reliability of this instrument with this sample was 0.81.

Spirituality. The caregiver's level of spirituality was assessed by 11 items ranked on a 4-point scale (1 to 4). The anchors were 1 "never or rarely", 2 "sometimes", 3 "often", and 4 "always or almost always". These items included content such as, "I accept the mysteries of life and death", and "I pray or meditate". A higher score was associated with stronger spirituality. This instrument was developed for use with this sample, and the reliability was 0.85.

Instruments Used to Measure the Bereaved Caregivers' Personal-Social Profile

Involvement in Care. Involvement with the patient was measured by an index consisting of 28 items that were answered by a "yes" or "no" and were scored 1 or 2, respectively. The items asked about the activities with which the patient needed help during the last four weeks of life, such as showering, dressing, and eating. A second area of this instrument asked for the amount of time spent caregiving and keeping company with the patient. The alpha for this sample was 0.74.

Burden of Care. This instrument assessed how providing care for the patient affected the caregiver's social activities, daily routines, and

relationships with others. A sample item would be, "I wish the family had depended less on me to care for the patient." Higher scores indicated a higher sense of burden from care. The instrument contained 38 items, scored on a 1 to 5 scale ("strongly agree" to "strongly disagree"). The alpha for this sample was 0.94.

Satisfaction With Support From Others. This instrument consisted of four items asking about the caregivers' relationships with friends, family members, community members, and church members in relation to their level of satisfaction with the support provided during the caregiving period. These items were on a 4-point scale in which 1 was "very dissatisfied", 2 "somewhat dissatisfied", 3 "somewhat satisfied", and 4 "very satisfied". The reliability of this instrument with this sample was 0.81.

Social Activities. The social activities scale, which included nine items, requested information on the frequency of contact with social supports since the death as compared with prior to the death. Items covered areas such as how frequently caregivers attended meetings and visited with neighbors and close friends. Each item related to the frequency of contacts and was rated from 1 to 3, where 1 indicated "more social activity than before the death", 2 indicated "less social activity", and 3 indicated "about the same level of social activity during the initial three month bereavement period as before the death". The reliability of this instrument with this sample was 0.74.

Instruments Used to Measure the Bereaved Caregivers' Health Status Profile

Health service utilization. This instrument assessed the use of 13 health services by the caregiver since the death of the patient. All items were "yes" or "no" responses, and included questions such as, "In the past three months, have you seen a doctor?", "In the past three months, have you had counseling for nerves, personal or family problems?", and "In the past three months, have you used Meals on Wheels?" The reliability for this instrument with this sample was 0.50.

Health Status. A set of six items asked about the caregivers' overall health. These items queried, for example, "How many days in the past three months have you felt ill?", and "How would you rate your health before and after your caregiving experience?" These were forced-choice items, with choices ranging from two to five options on various items. The reliability for this instrument with this sample was 0.73.

Instruments Used to Measure the Bereaved Caregivers' Financial Status

Income/Expenditures. The financial instrument asked caregivers about recent changes in their income and expenditures related to the final month of terminal care for their patient. These were primarily "yes" and "no" response items, with several items questioning specific dollar amounts for income and various expenses. Examples of the areas of change that were asked about include social security income, interest from stocks and bonds, welfare programs, life insurance, and inheritance income. There were 68 items on this instrument.

Employment. This tool consisted of 11 yes-or-no items. The queries included whether the caregiver was currently employed or had sought employment since the death of the patient. In another section, questions focused on whether caregiving had affected employment in various ways, e.g. "Did caring for your relative prevent you from looking for a job?", "Cause you to change jobs?", and "Cause you take a leave of absence?"

RESULTS

Demographics of Bereaved Caregivers and Deceased Patients

Approximately three quarters of the caregivers were female and married to the patient, and 92% had lived with the patient for an average of 30.8 years. The mean age of the caregivers at the beginning of the study was 56.8 years. The vast majority of caregivers were married (93.5%) and had less education than a college degree (82%) (Tables 1, 2).

The deceased patients had primarily lung (32.3%), breast (13.7%), and colon cancer (13.7%) and had a mean age of 62.2 years at the beginning of the study. The majority (54%) died at home. The number receiving hospice care or not was fairly evenly divided, with a few more patients not receiving hospice services.

Bereaved Caregivers' Psycho-Spiritual Profile

Depressive Symptomatology. The mean summed composite score for depressive symptomatology was 17.6 (SD 8.92, range 1-46), in which higher scores indicated greater depressive symptomatology. This mean score of 17.6 was above the mean score of 10 established for the general population (32,33). Table 4 shows comparisons with the other scaled measures.

Caregiver Depressive Symptomatology and Patient Age. An ANOVA was performed to determine the relationship between depressive symp-

Table 4 / OVERALL RESULTS FROM SCALED INSTRUMENTS (n=124)

Instrument	Mean	Standard Deviation	Range
Depression	17.60	8.92	1.00-46.00
Positive Outlook	2.48	0.66	1.00-4.00
Negative Reactions	1.34	0.36	1.00-2.80
Spirituality	3.13	0.55	1.60-4.00
Burden of Care	2.17	0.56	1.11-4.34
Satisfaction with Support	3.57	0.62	1.50-4.00

tomatology of the caregiver and the age of the patient. Using the median patient age of 64 to distinguish younger versus older patients, it was found that caregivers of younger patients (<64 years) reported significantly higher levels of depressive symptomatology than caregivers of older patients (>64 years). Their mean CES-D depression scores were 21.0 and 14.7 respectively, $F(1,122) = 14.73$, $p < .001$.

Positive Outlook. The mean composite score was 2.48 (SD 0.66, range 1-4). The higher the score, the greater the positive outlook of the bereaved caregiver. This sample reported the most positive outlook on three specific items: "Have you generally enjoyed the things you do?" (mean 2.72), "Have you felt that the future looks hopeful and promising?" (mean 2.61), and "Have you been satisfied or pleased with your personal life?" (mean 2.54).

Negative Reactions. This instrument had a mean composite score of 1.34 (SD 0.36, range 1-2.8) on a 1-4 scale. The most negative reaction was reported for the item, "Did you get frustrated with your situation?" (mean 1.9). The low means reported on this set of items indicated minimal negative reactions to caregiving.

Spirituality. The mean spirituality composite score was 3.13 (SD 0.55, range 1.6-4.0) on a 1-4 scale. The most highly endorsed items were, "I believe in a power greater than myself" (mean 3.65), "I know what is important in life" (mean 3.44), "My values and beliefs help me meet daily challenges" (mean 3.43), and "I accept the mysteries of life and death" (mean 3.42).

Bereaved Caregivers' Personal-Social Profile

Involvement in Care. Of the 28 items about involvement in care for activities of daily living and home adjustments to accommodate the patient, caregivers reported a mean of 12.3 activities in which they were involved during the last four weeks of the patient's life. The majority of the caregivers were involved in dressing the patient, combing their hair, bathing, toileting,

walking, getting around the house, getting in and out of bed, managing money matters, taking medications, arranging transportation, mouth care, lifting and turning, and incontinence care for urine accidents. The average number of hours of direct care by caregivers was 10.8 hours per day. Also reported was time spent keeping their patient company, with a mean of 8.9 hours per day. The majority (62%) had to make adjustments to their home, such as changing a bedroom to another location in the home or purchasing equipment, e.g. bed, urinal, assistive moving devices.

Burden of Care. The mean composite score for this instrument was 2.17 (SD 0.56, range 1.11–4.34) on a 1–5 scale. The items representing the highest burden for caregivers were, "I had eliminated things from my schedule while caregiving" (mean 3.57), "My activities were centred around caregiving" (mean 4.31), and "I had to stop in the middle of my work or activity to provide care" (mean 3.30).

Satisfaction With Support From Others. Overall the caregivers were satisfied with the social support they received during caregiving, with a mean of 3.57 (SD 0.62, range 1.50–4.00), in which 1 indicated "very dissatisfied" and 4 was "very satisfied". All four items had very similar means, with no one item standing out at a notably lower satisfaction level.

Social Activity Level Before and After Patient's Death. In terms of social activities, the majority (60.5%) of bereaved caregivers reported a similar level of social activity following the death of their patient. On average, 23.4% of caregivers reported more social activities than before the death, and 16.1% reported fewer social activities. However, 84% of the caregivers reported an increase in frequency of at least one area of social activity, with a mean of 2.8 (range 1–9) areas in which frequency of social contact increased.

Bereaved Caregivers' Health Status

Health Services Utilization. Of the 13 health services used in the three months since the death of the patient, the mean usage was 1.8 services, with a range of 1–8 services utilized. Fifty percent of caregivers reported office visits to their primary care provider and 30% reported consulting with their spiritual resource person, e.g. minister, priest, or rabbi.

Health Status. Three quarters of the caregivers reported no sick days in the three months since the death of their patient, whereas one quarter reported 1 to 30 days of illness. The mean

number of sick days of those who reported illness in the three months since the death was 1.4 days. Of the total sample, the majority (79%) rated their physical health as good or excellent and about the same as three months ago (69%). The majority (88%) rated their emotional health before caregiving as good or excellent; they also rated their current status as good or excellent (75%). When asked about new health problems since the death, the group was fairly evenly divided, with 42% reporting new problems and 57% reporting no new problems.

Bereaved Caregivers' Financial Status

Income/Expenditures. The majority (91%) of participants owned their own home and 90% reported no current difficulty in paying monthly bills. When asked about sources of income since the patient's death, approximately half of the respondents reported three sources: social security (48%), salary and wages (42%), and retirement pension (50%). Many had savings; 72% reported income from interest on stocks, bonds, and savings. Of the total sample, 81% reported a change in income since the death, with 56% of this subsample indicating this change was a decrease in income. The most frequently reported reason for the decrease in income was attributed to a reduction in social security benefits. Ten percent reported an increase in income (Table 5).

In the last month of their patient's life, 44% of the caregivers had out-of-pocket expenses that were not covered by insurance. Of this subsample, 52% had out-of-pocket expenses for medications, 41% for doctor bills, 32% had miscellaneous expenses such as incontinence pads and paid household help, 19% had hospital bills, 14% needed special medical equipment, 10% used visiting nurse services, and 1% had nursing home bills. When assessing the total amount paid out-of-

Table 5 / IMPACT ON CAREGIVER INCOME SINCE PATIENT'S DEATH

Sources of Income	Number	%*
Stocks/Bonds/Savings Interest	89	72%
Retirement Pension	62	50%
Social Security	59	48%
Salary/Wage	52	42%
Change in Income	Number	%
Decrease in Income	69	56%
Increase in Income	12	10%
No Change in Income	33	34%
Total	124	100%

* Percents do not total 100%, as some participants responded to more than one category

Mean income = US \$1706 per month, SD = \$1166, Range = \$300–5000

ocket during the last month of their patient's life, caregivers spent an average of \$529.00 (Table 6).

Those who reported how these out-of-pocket expenses were covered, 27% paid from savings, 21% paid from life insurance policies, 4% paid from estate monies, 4% sought out new employment, 3% paid by selling assets, and 1% took out loans (Table 7)

Table 6 / CAREGIVER OUT-OF-POCKET EXPENSES (n=124)

Type of Expense	Number	%	Mean	SD	Range
Doctor Bills	65	52%	\$130	\$167	\$6 - \$1000
Hospital	51	41%	\$251	\$574	\$4 - \$3500
Nursing Home	40	32%	\$130	\$113	\$20 - \$400
Medications	24	19%	\$722	\$1019	\$25 - \$3500
Visiting Nurse Services	17	14%	\$337	\$588	\$3 - \$2000
Special Medical Equipment	12	10%	\$1355	\$1537	\$200 - \$4700
Misc. (e.g., incontinence pads)	1	1%	\$200	—	\$200 - \$200

Total out-of-pocket expenses mean = \$529, SD = \$1137, Range = \$0-\$6,800

Table 7 / SOURCES OF PAYMENT FOR OUT-OF-POCKET EXPENSES FOR TERMINAL HEALTH CARE

Sources of Payment	Number	%
Savings	34	27%
Life insurance	5	21%
Estate monies	5	4%
New employment	5	4%
Sale of Assets	4	3%
Loans	1	1%

Employment. Three months after the death of their patient, 35% of caregivers were employed; 26% of this subsample were employed full-time and 9% part-time. Of those who reported their type of employment, 37% were in professional positions, 34% in sales or clerical services, 15% were craftsmen, and 15% were manual laborers. Another 39% were retired caregivers, with the majority having been in professional or sales positions before retirement. Ten percent of caregivers were currently looking for employment, and 7% took a job after the death of their patient. The majority (67%) of the subsample who took a job after the death did so to cover personal finances.

When asked about how caregiving affected their employment, 35% reported decreasing the number of hours worked, 11% reported that caregiving prevented them from looking for a job, 11% reported that caregiving caused them to quit a job, 9% reported refusing a job opportunity due to caregiving responsibilities, and 4% reported declining a better job. In addition, 41% found some disruption to their employment as a result of caregiving, 32% missed days of work to provide care, 12% took a leave of absence from work during terminal caregiving, 7% took an early retirement to provide care, and 2% had to change jobs to accommodate caregiving. Employed caregivers missed, on average, 14 days (SD 18 days, range 0-90) of work during the last three months of their patient's life in order to provide care.

Correlational Analyses. Correlations were calculated between the instruments for which it was possible to calculate a mean (Table 8). Because the income and employment question-

Table 8 / CORRELATION MATRIX OF INSTRUMENTS

	Depression (CES-D)	Positive Outlook	Negative Reactions	Spirituality	Involvement	Burden of Care	Satisfaction with Support	Social Activities	Health Service Utilization
Depression (CES-D)	1.00	-0.82**	0.26**	-0.36**	0.05	0.17	-0.27**	-0.17	-0.08
Positive Outlook	-0.82**	1.00	-0.32**	0.39**	-0.12	-0.24**	0.32**	0.13	-0.07
Negative Reactions	0.26**	-0.32**	1.00	-0.31**	0.12	0.62**	-0.42**	-0.07	0.08
Spirituality	-0.36**	0.39**	-0.31**	1.00	-0.12	-0.30**	0.27**	0.11	0.15
Involvement	0.05	-0.12	0.12	-0.12	1.00	0.27**	-0.20*	-0.05	0.19
Burden of Care	0.17	-0.24**	0.62**	-0.30**	0.27**	1.00	-0.48**	-0.08	0.23*
Satisfaction with Support	-0.27**	0.32**	-0.42**	0.27**	-0.20*	-0.48**	1.00	0.08	0.00
Social Activities	-0.17	0.13	-0.07	0.11	-0.05	-0.08	0.08	1.00	0.02
Health Status	0.43**	-0.44**	0.17	-0.07	0.16	0.19*	-0.12	-0.02	0.24*

*p<0.05; **p<0.01

Table 9 / CORRELATION MATRIX BETWEEN EMPLOYMENT AND OTHER INSTRUMENTS

	Depression (CES-D)	Positive Outlook	Negative Reactions	Spirituality	Involvement	Burden of Care	Satisfaction with Support	Social Activities	Health Service Utilization	Health Status
Employed for pay	-0.02	0.02	-0.27**	0.12	-0.01	-0.11	0.12	0.10	0.11	0.09
Take job after patient's death	-0.33**	0.26*	0.02	0.17	0.09	-0.02	0.11	-0.11	0.08	-0.14

*p<0.05; **p<0.01

Table 10 / CORRELATION MATRIX BETWEEN INCOME AND OTHER INSTRUMENTS

	Depression (CES-D)	Positive Outlook	Negative Reactions	Spirituality	Involvement	Burden of Care	Satisfaction with Support	Social Activities	Health Service Utilization	Health Status
Caregiver monthly income	-0.21*	0.16	0.10	-0.01	-0.07	0.05	-0.19*	0.11	-0.12	-0.23*
Change in caregiver monthly income	-0.19*	0.17	-0.12	0.14	0.06	-0.08	-1.0	-0.03	-0.18	-0.16

*p<0.05

naires contained items that could not be combined into a mean scale score, individual items from these measures were selected to be correlated with the other scales. The items that significantly correlated with one or more scales are presented in Table 9 (employment items) and Table 10 (income items).

Depressive symptomatology was negatively correlated with positive outlook, satisfaction with support, taking a job after the patient's death, caregiver monthly income, and change in income. Positive outlook was positively associated with satisfaction with support and taking a job after the patient's death.

Negative reactions were positively associated with depressive symptomatology and burdens of care and were inversely correlated with positive outlook, spirituality, satisfaction with support, and being employed for pay. Spirituality was positively correlated with positive outlook and satisfaction with support and was inversely associated with depressive symptomatology, negative reactions, and burden of care.

Burden of care was positively correlated with involvement in care and health service utilization and was inversely correlated with positive outlook and satisfaction with support. Satisfaction with support was positively correlated with positive outlook and was inversely related to involvement in care and monthly income. Poor health status was positively correlated with depressive symptomatology, burden of care, and health service utilization.

Poor health status was negatively correlated with positive outlook and monthly income.

DISCUSSION

This sample was principally composed of female caregivers who were married to their patients. These bereaved caregivers possessed a complex combination of emotional, physical, and spiritual characteristics along with very practical financial and employment concerns.

In the area of psycho-spiritual well-being, this sample expressed more depressive symptomatology than the general public but had an above-average positive outlook and sense of spirituality along with minimal negative reactions to their caregiving experience. Not surprisingly, depressive symptomatology was positively correlated with negative reactions and inversely correlated with positive outlook and spirituality. Kurtz and colleagues (34) reported that bereaved caregivers were likely to experience depressive symptomatology after the death of the patient.

Further, negative reactions were inversely correlated with spirituality and positive outlook. It appears that these caregivers did not harbor negative feelings about their role as caregiver, and their positive outlook and strong sense of spirituality may have been a helpful combination in counteracting their depressive symptomatology. Carson (35) suggested that the health professional can support the caregiver through the dying process by acknowledging

the importance of physical, emotional, and spiritual self-care. This attitude encourages caregivers to pay attention to personal needs as well as to the needs of their dying patient. Caregivers need encouragement to express their feelings and to stay connected with others who sustain them. This type of intervention during caregiving can then serve as a supportive link through the death and into bereavement.

It may also take more than three months (the timing of the bereavement interview) to begin to rebound from depressive symptomatology. Interventions for the bereaved caregiver could be targeted both to help with emotional fluctuations and to enhance their reported positive outlook. Many hospice organizations provide follow-up bereavement care that incorporates such support. However, only about half of this sample were involved with hospice. No matter where the caregiver is in the health care system at the time of death, health professionals need to consider their supportive needs and include them in a total plan of family care. Specifically, health professionals could provide pamphlets or follow-up phone calls with information on community resources for recently bereaved individuals.

In the area of personal-social well-being, caregivers had a relatively high level of involvement in basic care and support for the patient, reported a moderate level of burden from the care they provided, and were quite satisfied with the support they received from others during terminal caregiving. This is a fairly promising prognosis for the personal and social recovery of the caregiver. However, those who reported the greatest burden were more highly involved and significantly less satisfied with support from others. It appears that some caregivers had shifted a great deal of time and energy into caregiving activities and acknowledged that this represented a moderate burden. On the other hand, they felt that their social network had readily welcomed them back to previous social activities after the death.

Health professionals could work closely with caregivers during the caregiving phase to help them remain aware of how their lives are displaced for this period of time but that they will eventually have their own time available again. In this way, the health professional can assist caregivers to see a portion of their life as separate from their caregiver role. This separate identity could help the caregiver maintain a sense of personal purpose in life that could be cultivated again following the death.

The bereaved caregivers were found to be relatively healthy, both physically and emotion-

ally. Although poor health status and health service utilization were significantly correlated, the majority of caregivers had utilized health services in the three months since the death. These were mainly office visits to primary care providers rather than acute crises or hospitalizations. As there appears to be a high number of primary care visits during early bereavement, this provides the health professional an excellent opportunity to assess and intervene on the emotional as well as physical areas of need. Scanlon (36) points to the efforts of the American Nurses Association (ANA) to provide position statements on the nurse's role in end-of-life care. The ANA is committed to providing leadership for engaging in professional and public dialogue about end-of-life issues and to shape the development of systems of care that respond sensitively and appropriately to families and patients during their final days. Health professionals can take an active role in determining caregiver needs and then implementing specific, targeted interventions during terminal care and into early bereavement.

On the practical front, these caregivers experienced substantial financial changes and had to make numerous employment and financial adjustments during caregiving and after the death of their patient. No less than 81% of this sample reported a financial adjustment. Income and/or employment were negatively correlated with the following scales: health status, negative reactions, depressive symptomatology, and satisfaction with support. These correlations, along with individual item analysis, indicate that there were multiple out-of-pocket expenses during the last month of life and many disruptions to employment to accommodate caregiving. However, taking a job after the patient's death was positively associated with positive outlook and negatively related to depressive symptoms, suggesting that returning to work may offer social support or other diversions for the bereaved caregiver.

As bereavement care becomes more a part of our societal values, support sessions on financial and employment planning could become a standard part of care. This could begin prior to the death of the patient, in terms of estate planning, employee benefit packages, and insurance benefits. If a caregiver is unable to cope with additional information prior to the death, classes could be offered during the bereavement period to help with managing available funds, accessing all sources of income to which they are entitled, and making long-term personal finance and retirement plans. These are practical issues that often cause great hardship for bereaved

caregivers, especially if they have not been the primary financial manager in the family. Specifically, health care providers could have community resources readily available for caregivers, which would decrease barriers to accessing help at a time when they are likely to feel emotional and vulnerable. Health care agencies are constantly looking for ways to increase client satisfaction and provide useful amenities. This may be a practical way to meet a pressing need at a critical time. In truth, caregivers are the ongoing patient in the system, and appropriate assistance at a crucial time may help maintain the bereaved caregiver's own health.

Overall, the bereaved caregiver presented a hopeful profile with a high likelihood for recovery from the personal and social sacrifices made during caregiving. However, it may take somewhat longer to adjust to the financial losses imposed by caregiving and by the death. There are clearly many ways in which health professionals can intervene during terminal caregiving and early bereavement to support caregivers with emotional, physical, and practical matters, so that their health does not significantly deteriorate in the process and they are able to regain their pre-caregiver roles in optimal time.

Although these data present a useful profile of the bereaved caregiver, possible limitations should be noted. This was a convenience sample, and the majority of instruments were specifically designed for this study. With the exception of the CES-D scale, they lacked established reliability. Further, the results are quite specific to caregivers of patients in the United States with major life-threatening cancers, who are financially able to own a home, and who are female spouses of the patients. Generalizability to other caregivers is unknown.

Cancer continues to be the second leading cause of death in the United States today. Therefore, health professionals must be well informed about the end-of-life care needed and comfortable discussing these issues with families. There will be an increased need for terminal caregiving and for assistance to the caregiver in coping with the emotional, physical, spiritual, and practical difficulties that occur during caregiving, death, and bereavement. As health professionals, we must acknowledge the graying of America as the baby boom generation moves into the ranks of senior citizens (37). No longer can hospice personnel be expected to cover all terminal care needs and bereaved caregiver concerns. Terminal care and bereavement support must be incorporated into all health professional programs and be modeled by supportive mentors and teachers.

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A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

1998-1999 DOD GRANT ABSTRACTS Appendix D

Rovoll, M.D. & **Wyatt, G.K.** (1999, May). The challenges of quality assurance in data entry. Michigan Family Practice Research Day. Published in Proceedings Book, p.8.

Beckrow, K.C., **Wyatt, G.K.**, Given, C.W., & Given B.A. (1999, April 20). A conceptual model for an in-home nursing intervention following short-stay surgery for breast cancer. Seventh Annual Greater Lansing Nursing Research Day. Published in Proceedings Book.

Wyatt, G.K., Given, B.A., & Given, C.W. (1998, November). Nurse-sensitive outcomes for the short-stay breast cancer patient. Oncology Nursing Society's State-of-the-Knowledge Conference on Nurse-Sensitive Outcomes. Published in Proceedings Book, p. 35.

THE CHALLENGES OF QUALITY ASSURANCE IN DATA ENTRY

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Quality Assurance (QA) is an essential aspect of data management in research. The purpose of this paper is to share a QA protocol for the computerized nursing care document system of the study, "A Subacute Care Intervention for Short-Stay Breast Cancer Surgery," (#DAMD17-96-1-6325) funded by the Department of Defense. Over the four years of the study, 200+ women who have undergone short-stay breast cancer surgery are enrolled in this randomized clinical trial. Nurses chart on nursing diagnoses, symptoms experienced, and interventions implemented. Data is then transcribed into the computerized documentation system. The QA protocol is initiated by cross-referencing the paper chart with the computer documentation. Assurances must be made that data entry was correct, consistent, and that all protocol data was addressed. Any inconsistencies must be clarified with the nurse and corrections made on the computerized system before data is ready for analysis. The challenges of this QA process will be outlined.

**A CONCEPTUAL MODEL FOR AN IN-HOME NURSING INTERVENTION
FOLLOWING SHORT-STAY SURGERY FOR BREAST CANCER**

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With the current early discharge trend for breast cancer surgery, women are often sent home from the hospital within hours rather than days. Many are left to care for themselves or depend on family members to provide support, and most have no prior experience with post-surgical care. This lack of knowledge and experience often leads to feelings of anxiety, the development of physical complications, and greater out-of-pocket costs related to care. Through funding from the federal government, a randomized clinical trial entitled "A Subacute Care Intervention for Short-Stay Breast Cancer Surgery" (DAMD17-96-1-6325) is testing a conceptual nursing care model that targets key outcome variables associated with short-stay surgery including emotional well-being, physical recovery, and out-of-pocket costs. Data are collected at baseline, four weeks post-surgery, and four months post-surgery through the use of self-administered questionnaires, telephone interviews, and chart audits. The study sample includes women 21 years of age or older with a positive diagnosis of breast cancer who are undergoing short-stay surgery (48 hours or less), including lumpectomy with axillary node dissection, mastectomy with node dissection, or mastectomy without node dissection. While data are too limited at this time to report conclusive findings, trends indicate that data from the study will help define the physical and emotional nursing care needs for short-stay breast cancer patients.

NURSE-SENSITIVE OUTCOMES FOR THE SHORT-STAY BREAST CANCER PATIENT

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With the advent of short-stay and out-patient breast cancer surgery many women are experiencing a gap in both physical and emotional care. Prior to surgery, women are faced with the diagnosis of cancer, selecting the type of surgery which is best for them, and deciding on whether or not to have immediate reconstructive surgery. Following surgery, many are sent home to care for themselves or depend on family members to provide support. This can lead to feelings of anxiety, and the potential emergence of multiple psycho-social and post-operative complications. The purpose of this paper is to share post-surgical nurse sensitive outcomes from our four year "Nursing Care for Breast Cancer Study," funded by the Department of Defense # DAMD17-96-1-6325. Over the four years of the study, 200 + women who have had short-stay (48 hours or less) breast cancer surgery will be enrolled in a randomized clinical trial. Women in the intervention arm will receive phone contacts and care in the home by a registered nurse during the first two weeks following surgery. The protocol of care includes physical assessment, symptom management, incision self-care, drainage management, teaching/learning on breast self exam, lymphedema prevention, and range-of-motion of the affected arm. The framework guiding the protocol is one of self-care and empowerment so that women can become pro-active on their own behalf. With the nurse-patient interaction, it is intended that problems will be identified and addressed as they arise, rather than developing into serious complications during the early post-operative days when the patient is between phases-of-care in the formal health care system, i.e., surgery and follow-up treatment. We are interested in documenting the appropriate dose and protocol-of-care needed for timely, cost effective, and patient-satisfying outcomes from short-stay breast cancer surgery.

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

GRADUATE STUDENT THESIS ABSTRACT
Appendix E

Bloomfield, M. (1999). The effects of early versus delayed exercise on seroma formation and range-of-motion recovery in short-stay breast cancer surgery patients.

POST-DISCHARGE SEROMA FORMATION FOLLOWING BREAST CANCER
SURGERY: IMPLICATIONS FOR THE ADVANCED PRACTICE NURSE

By

Mary J. Bloomfield

A THESIS

Submitted to

Michigan State University

in partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE IN NURSING

College of Nursing

1999

ABSTRACT

POST-DISCHARGE SEROMA FORMATION FOLLOWING BREAST CANCER SURGERY: IMPLICATIONS FOR THE ADVANCED PRACTICE NURSE

By

Mary J. Bloomfield

Medical management of breast cancer patients in the United States has changed dramatically in recent years, largely in response to rising health care costs. A variety of surgical procedures are available, including the traditional modified radical mastectomy and new, breast-conserving techniques. Hospital stays of 24 hours or less have become the norm, and patients are expected to perform more self-care actions during their recovery at home. Among these actions is recognition of surgical complications, the most common being seroma formation, a potentially infectious accumulation of fluid in the surgical site. The etiology of seroma is unknown, and prevention is problematic.

Results of this secondary analysis of the federal grant, *A Subacute Care Nursing Intervention for Short-Stay Breast Cancer Surgery* (DAMD17-96-1-6325), Gwen Wyatt, RN, PhD, Principle Investigator, suggest that women undergoing traditional surgery were at five times greater risk for seroma formation compared to women receiving breast-conserving surgery, regardless of the type of post-discharge care they received, or personal characteristics such as body mass index or age. Implications for the Advanced Practice Nurse (APN) on the interdisciplinary team include educating patients about seroma formation, facilitating self-care, and collaborating with tertiary providers in order to prevent serious sequella.

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

GRANT PROPOSAL ABSTRACTS

Appendix F

Wyatt, G.K., Collins, C., & Bradley, C. (1999). Improving Outcomes Through a Supportive Intervention: A Continuum of Holistic Care. Submitted to the Department of Defense. Submission date: July 28, 1999.

Wyatt, G.K., Given, B.A., & Given, C.W. (1999). Supportive Care for Women with Late Stage Breast Cancer. Submitted to the Center of Alternative Medicine (CAM) and the National Institutes of Health (NIH). Submission date: May 24, 1999.

Improving Outcomes Through a Supportive Intervention: A Continuum of Holistic Care

Clinical Translational Research Award Proposal

Submitted by:

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TECHNICAL ABSTRACT

The purpose of the proposed study is to test the effect of a two-tiered intervention designed to promote optimal well-being among women with breast cancer during the immediate post-surgical period, the adjuvant treatment phase, and into extended survivorship. This study will build upon the present DoD study which is a randomized clinical trial testing a nursing care intervention during the two weeks immediately after short-stay breast cancer surgery, and assessing the associated costs. The second tier in the program of care is to follow a sample of women into adjuvant treatment, and extended survivorship with a yoga-based education intervention. This evolving conceptual framework will create an innovative and seamless continuum of care for women with breast cancer. Such an uninterrupted program of care will have substantial clinical impact not only by improving quality of life for women with breast cancer, but on cost containment for health care delivery.

A common baseline experience will be created for all participants by having everyone (n=200) receive our established post-surgical home care protocol during the first two weeks after surgery. Then, participants will branch into a **two group randomized clinical trial**. The **control group (n=100)** will receive an information packet outlining the customary community-based support services, and will be encouraged to avail themselves of these services during the 8 weeks following their 2 weeks of post-surgical home care. The **experimental group (n=100)** will receive a focused nursing intervention consisting of supportive care components during 8 weekly sessions (2 hours in length) held in their local community. Each session will include, 1) an educational component addressing key concerns of women during adjuvant therapy and in preparation for survivorship, and 2) a yoga-based integration of these educational concepts through a program of stretching, breathing exercises, and relaxation techniques. Each group will also proceed with their conventional adjuvant care schedule.

The objectives of the intervention are to: 1) promote post-surgical recovery through a home based nursing component in the first two weeks following breast cancer surgery; 2) increase women's understanding of adjuvant treatment and survivorship issues, and self-care strategies for management of symptoms and emotional well-being through a group-based educational component; and 3) enhance quality of life, and emotional and physical well-being during adjuvant treatment and extended survivorship through a yoga-based educational program emphasizing upper body mobility, deep relaxation techniques, and breath awareness.

Through a randomized clinical trial of post-surgical patients with breast cancer, we hypothesize that those who receive conventional care plus an 8 week restorative protocol following 2 weeks of post-operative nursing care, when compared to a control group (who received only conventional care and 2 weeks of post-operative care) will report significantly: 1) decreased anxiety, 2) decreased depression, 3) higher functional status, 4) fewer symptoms (especially fatigue), 5) improved arm/shoulder range of motion, 6) lower costs for health services, 7) minimized loss of productivity cost, and ultimately, 8) higher quality of life.

Supportive Care for Women with Late Stage Breast Cancer

Submitted to the National Institutes of Health
in response to
PA-98-019 "Management of Symptoms at the End of Life"

Submitted by:

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ABSTRACT

The goal of this study is to test a nursing intervention that will assist in controlling symptoms at the end of life for women experiencing late stage breast cancer. Through improved symptom management, patients and caregivers will experience a higher quality of life and their caregivers will perceive less distress as well as a higher quality of life. With improved quality of life, patients will be in a better position to make significant end of life choices. This randomized clinical trial will test three distinct groups, and run for eight weeks, involving both the patient and family caregiver. The control group will receive conventional medical care. The intervention A group will receive symptom management education and guided imagery. The intervention B group will receive symptom management education, guided imagery, and reflexology. The value-added effect to conventional care by complementary therapies with groups A and B will be tested. It is hypothesized that group A (education and imagery) will have significantly better outcomes than the control group (conventional care). Further, it is anticipated that the significant difference between the control group (conventional care) and intervention group B (education, imagery, and reflexology) will be higher than between the control group (conventional care) and intervention group A (education and imagery). If the complementary therapy groups (A and B) of this study prove useful, this study has the potential of leading to the integration of conventional and complementary cancer care into an improved supportive care system.