



# Quality of Life in Breast Cancer Survivors

Policy and Procedures Manual  
Version 2  
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Manual edited by NCI to reflect program implementation protocol only--not research protocol.

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Project Years: 2001-2005

## SECTION V: INTERVENTION

### Standardized BCEI Protocol - Experimental Group

#### Introduction

Implementation of the BCEI visits will be at a site of the subject's preference, typically the home. The Research Nurse will call and make arrangements to see the subject. At the first visit, the Research Nurse will provide the baseline QOL measures and instruct the subject to complete them. Next, the Research Nurse will deliver and tape-record each of three BCEI sessions. It is anticipated that this will take approximately 1-2 hours. The Experimental Group subjects will receive a total of five visits over six months. The Waiting Control group will receive six visits over seven months. Details of the process of implementing the BCEI sessions are as follows:

#### Outline of the BCEI Intervention

BCEI Session	Content	Time
<p style="text-align: center;"><b>Session #1</b> <b>Physical Well being</b></p> <p style="text-align: center;"><b>Pain</b> <b>Fatigue</b></p>	<ul style="list-style-type: none"> <li>▪ General introduction about the purpose of BCEI</li> <li>▪ Elicit subject's continued willingness to participate &amp; answer questions</li> <li>▪ Provide teaching about physical side effects (i.e., cancer-related fatigue and pain)</li> <li>▪ Develop skills to assess and communicate these QOL problems</li> <li>▪ Discuss range of interventions to manage these problems</li> <li>▪ Select appropriate interventions</li> <li>▪ Review skill building management techniques</li> <li>▪ Use BCEI Log to document the selected intervention, number of interventions, and effectiveness of interventions</li> <li>▪ Give BCEI Teaching Material and BCEI audiotape to subjects</li> </ul>	<ul style="list-style-type: none"> <li>▪ 5 min</li> <li>▪ 40 min</li> <li>▪ 5 min</li> <li>▪ 5 min</li> <li>▪ 5 min</li> </ul>
<p style="text-align: center;"><b>Session #2</b> <b>Psychological and Social Well being</b></p> <p style="text-align: center;"><b>Sexuality/fertility</b> <b>Fear of recurrence</b></p>	<ul style="list-style-type: none"> <li>▪ Review BCEI and answer questions about pain and fatigue</li> <li>▪ Elicit subject's willingness to continue participating</li> <li>▪ Verify BCEI Log information and collect BCEI Log</li> <li>▪ Discuss concerns about psychological and social well-being with respect to fear of recurrence and sexuality/fertility</li> <li>▪ Develop skills to assess and communicate these QOL problems</li> <li>▪ Discuss range of interventions to manage these problems</li> <li>▪ Select appropriate interventions</li> <li>▪ Review skill building management techniques</li> <li>▪ Review BCEI Log to document the selected intervention, number of interventions, and effectiveness of interventions</li> </ul>	<ul style="list-style-type: none"> <li>▪ 10 min</li> <li>▪ 40 min</li> <li>▪ 5 min</li> <li>▪ 5 min</li> </ul>

<p><b>Session #3</b> <b>Spiritual Well being</b> <b>Meaning in illness</b></p>	<ul style="list-style-type: none"> <li>▪ Review BCEI and answer questions about sexuality/fertility and fear of recurrence</li> <li>▪ Elicit subject's willingness to continue participating</li> <li>▪ Verify BCEI Log information and collect BCEI Log</li> <li>▪ Discuss concerns about spiritual well being with respect to meaning in illness</li> <li>▪ Develop skills to assess and communicate these QOL problems</li> <li>▪ Discuss range of interventions to manage these problems</li> <li>▪ Select appropriate interventions</li> <li>▪ Review skill building management techniques</li> <li>▪ Review BCEI Log to document the selected intervention, number of interventions, and effectiveness of interventions</li> <li>▪ Thank subject for participating in the BCEI and review the next steps in participating in the research project</li> </ul>	<ul style="list-style-type: none"> <li>▪ 10 min</li> <li>▪ 5 min</li> <li>▪ 20 min</li> <li>▪ 10 min</li> <li>▪ 10 min</li> <li>▪ 5 min</li> </ul>
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The BCEI teaching sessions are conducted by the Research Nurses but the written materials and audiotaped versions will be given to each subject for reinforcement of teaching. Follow-up evaluation visits will occur at Month-3 and Month-6. The Waiting Control group will receive the initial evaluation during Month-1, but will not receive the BCEI until month 6. Follow-up evaluations are planned at Month-3 and Month-6 that correspond to the same post-intervention evaluation as the Experimental group. The Waiting Control group will receive the BCEI intervention in Month-6 (please see following procedure). The Waiting Control group will receive one follow-up evaluation at Month-7. This design has the advantages of randomization with the benefit of providing the BCEI to all subjects. Implementation of the BCEI will span Year-1 Month-7 to Year-4, Month-2.

The purpose of the BCEI is to provide standardized educational information, skills training, and homework for women with breast cancer.

**Time Frame**

The standardized BCEI intervention will be implemented in three approximate one-hour individualized sessions.

**Methods**

1. Patient who has met the inclusion criteria will have signed the consent form and completed the baseline questionnaires.
2. The patient will be informed to which group they have been assigned and appointments for the BCEI intervention will be arranged with the experimental group.(see procedure for randomization in the next section for details)
3. The Research Nurse will meet with the patient on three occasions and deliver the BCEIs. The first session may be immediately following filling out the baseline questionnaires. .

4. The patient will receive a reinforcement call from the Research Nurse in the second, fourth and fifth month of their enrollment into the program. At the 2 and 5 month call arrangements will be made for an appointment to fill out their 3 and 6 month questionnaires.

## **Standardized BCEI Protocol - Wait Control Group**

### **Introduction**

Implementation of the BCEI visits will be at a site of the subject's preference, typically the home. The Research Nurse will call and make arrangements to see the subject for Month 6 data collection and to schedule the educational sessions.

At this visit, Month 6 questionnaires will be filled out by the patient and the educational sessions will start.

We acknowledge the fact that concerns that were present at the beginning of the study may no longer be a concern for the patient. Discuss present concerns with the patient and offer individualized education.

#### Options:

- 3 formal educational sessions covering the 5 topics in detail, review sheets will be completed with the patient
- 2 formal educational sessions covering the 5 topics in detail, review sheets will be completed with the patient
- 1 educational session that focuses on the issues and concerns the patient has at this time, review sheets will be completed with the patient
- Self study if the patient does not have any concerns at this time, review sheets will be completed with the patient

These options allow for individualized education to be delivered in a time efficient manner. For all options, the research nurse will evaluate the problems and concerns and offer tip sheets as appropriate. The educational sessions will not be taped for the wait-controlled group. Time per visit will vary.

This design has the advantages of randomization with the benefit of providing the BCEI to all subjects.

### **Outline of the BCEI Intervention**

<b>BCEI Session</b>	<b>Content</b>	<b>Time</b>
<b>Session #1</b> <b>Physical Well being</b>  <b>Pain</b> <b>Fatigue</b>	<ul style="list-style-type: none"> <li>▪ General introduction about the purpose of BCEI</li> <li>▪ Elicit subject's continued willingness to participate &amp; answer questions</li> <li>▪ Provide teaching about physical side effects (i.e., cancer-related fatigue and pain)</li> <li>▪ Develop skills to assess and communicate these QOL</li> </ul>	<ul style="list-style-type: none"> <li>▪ Times will vary according to patient need</li> </ul>

	<p>problems</p> <ul style="list-style-type: none"> <li>▪ Discuss range of interventions to manage these problems</li> <li>▪ Select appropriate interventions</li> <li>▪ Review skill building management techniques</li> <li>▪ Use BCEI Log to document the selected intervention, number of interventions, and effectiveness of interventions</li> <li>▪ Give BCEI Teaching Material and BCEI audiotape to subjects</li> </ul>	
<p><b>Session #2</b> <b>Psychological and Social Well being</b></p> <p><b>Sexuality/fertility</b> <b>Fear of recurrence</b></p>	<ul style="list-style-type: none"> <li>▪ Review BCEI and answer questions about pain and fatigue</li> <li>▪ Elicit subject's willingness to continue participating</li> <li>▪ Verify BCEI Log information and collect BCEI Log</li> <li>▪ Discuss concerns about psychological and social well-being with respect to fear of recurrence and sexuality/fertility</li> <li>▪ Develop skills to assess and communicate these QOL problems</li> <li>▪ Discuss range of interventions to manage these problems</li> <li>▪ Select appropriate interventions</li> <li>▪ Review skill building management techniques</li> <li>▪ Review BCEI Log to document the selected intervention, number of interventions, and effectiveness of interventions</li> </ul>	<ul style="list-style-type: none"> <li>▪ Time will vary according to patient need</li> </ul>
<p><b>Session #3</b> <b>Spiritual Well being</b></p> <p><b>Meaning in illness</b></p>	<ul style="list-style-type: none"> <li>▪ Review BCEI and answer questions about sexuality/fertility and fear of recurrence</li> <li>▪ Elicit subject's willingness to continue participating</li> <li>▪ Verify BCEI Log information and collect BCEI Log</li> <li>▪ Discuss concerns about spiritual well being with respect to meaning in illness</li> <li>▪ Develop skills to assess and communicate these QOL problems</li> <li>▪ Discuss range of interventions to manage these problems</li> <li>▪ Select appropriate interventions</li> <li>▪ Review skill building management techniques</li> <li>▪ Review BCEI Log to document the selected intervention, number of interventions, and effectiveness of interventions</li> <li>▪ Thank subject for participating in the BCEI and review the next steps in participating in the research project</li> </ul>	<ul style="list-style-type: none"> <li>▪ Times will vary according to patient need</li> </ul>

The BCEI teaching sessions will be conducted by a Research Nurse. The written materials and audio taped versions will be given to each subject for reinforcement of teaching. Follow-up evaluation visit will occur at month 7. Prior to the education session(s), the patient will have received Telephone reinforcement calls at Month 2, 4 & 5, and Data Collection visits at Month 3.

## **Procedure for Randomization to Experimental or Control Groups**

A table of paired randomization will be created by Dr Zhang of the Statistics Department at UCF. The subjects will be separated by age and race and by referring cancer centers location, creating eight subtables: Young (50 years of age or younger) white; young, non-white; old (51 years or older) white and old, nonwhite. MDACCO and self referrals will have one table. Subjects recruited from other centers will share another table. The research nurse will determine which category the participant is in and will determine the group (experimental or wait control) on the basis of the randomization table at the time the consent is signed.

## **BCEI Intervention Talking Points**

### **Purpose**

The purpose of this section is to facilitate the Research Nurse's ability to implement the BCEI intervention protocol in a standardized manner.

### **Time Frame**

The first standardized BCEI session is implemented after baseline measures are taken in the experimental group. The second and third sessions are implemented within one month of the first BCEI ideally at one-week intervals.

### **Supplies:**

1. Research Nurse's script and binder
2. *Consent forms x2*
3. Pens
4. Business cards
5. Tape recorder and extra batteries to tape the session
6. Blank tape
7. Randomization envelope
8. Welcome letter
9. Directions
10. Patient file
11. Instruments
12. *Patient binder with first two modules*
13. *Audiotape: Fatigue and Pain*
14. *Tip sheets*
15. Highlighter
16. *Tape recorder for the patient to borrow*

The *italicized items* are only necessary if the patient is in the experimental group and she will be signing the consent and completing the baseline questionnaires on that day.

## **BCEI – 1 Introduction and First Session Guidelines**

**\*\*\*NOTE\*\*\***

**These guidelines should accompany the guidelines for baseline data collection in experimental patients and by the guidelines for the third data collection for wait control patients.**

For the experimental subject, remind them that the intervention will be tape recorded for quality assurance purposes. Assure the subject that they will not be identified on the tape and only the principle investigator listens to the tapes. They are randomly chosen and erased after review.



## Outline of Essential Information – Fatigue & Pain modules

*Feel free to ask the subject about her experience at any time during the lesson, and elaborate or minimize material as needed, but be sure to address all the information in the outline. This is important for consistency of the intervention.*

### I. Introduction of Fatigue

- A. In this section, first we will discuss fatigue in general and the factors related to, how you can communicate your fatigue to others. We will be discussing what you have tried to help with fatigue and then I'll have some homework for you.
- B. definition of fatigue: a feeling of unpleasant weariness, exhaustion or lack of energy.
- C. most common side effect of cancer treatment
- D. can last for months after treatment ends
- E. Have you experienced fatigue?

### II. Overview of Fatigue (If you want to follow along- pg. 1)

- A. Symptoms of Fatigue
  - 1. teary, weepy
  - 2. irritable
  - 3. fuzzy droopy
  - 4. too tired to do everyday activities- housework showering cooking walking
  - 5. difficulty thinking or making decisions
  - 6. Have you had any of these symptoms? (pause for response)

Now we'll be discussing some of the main factors that affect fatigue in Breast cancer survivors:

- B. Insomnia
  - 1. symptoms
  - 2. Sleep Hygiene
  - 3. Tip Sheet available

### C. Anemia

1. Definition
2. Severe vs. chronic
3. Tip Sheet available on Anemia Management

### D. On the next page - Nutrition

1. Iron rich foods green leafy vegetables and meats
2. Adequate caloric intake
3. Frequent small meals
4. Wt gain after treatment can be a problem
5. Tip Sheet available on nutrition to manage fatigue

### E. Exercise

1. Exercise actually improves fatigue.
2. Also helps with weight gain.
3. Tip Sheet available

### F. Medications

1. Classes that increase fatigue
2. Do you take any medications that you think may be causing you to feel fatigued.
3. Ways to minimize side effects Tip Sheet available

### G. Mental fatigue

1. Definition- difficulty exerting mental energy
2. Symptoms
  - a) Difficulty concentrating,
  - b) focusing
  - c) problem solving
3. Ways to minimize

- a) Relaxation
  - b) Distraction
  - c) Stay in the moment
4. Tip sheet for mental fatigue

#### H. Fatigue in the workplace

- 1. problem with concentration or lack of energy
  - 2. Bosses/co workers may not understand/ can get irritated
- Tip sheets available with ways you can manage your fatigue at work/  
tips for talking to your employer...

### III. Assessment and evaluation of your fatigue (Page 4)

- A. Scale 1-10
- B. Self evaluation Questions (show them the list- go over a few questions with them and ask them to answer them for themselves during the week.)
- C. Keep a diary about your fatigue

### IV. Communicating about Fatigue

- A. Family
- B. Oncology team
  - 1. change treatment

### V. Review of Your Fatigue (fill out the form with the patient)

- A. What are your problems with pain
- B. Current treatments
- C. How are they working
- D. Suggested treatments/Tip sheets  
(take the sheet for baseline information and write the subject # on top right corner.)

## VI. Homework

- A. Go over pages with patient
- B. Practice the suggestions on the tip sheets
- C. Feel free to jot down any questions or comments you may have in here, so we can go over them next week.

## VII. Introduction to pain

- A. In this section first we will discuss pain in general and the factors related to breast cancer that may affect pain, then we will look at your pain and talk about how you can communicate your pain to others. We will be discussing what you have tried to help with pain and then I'll have some homework for you.
  
- B. definition of pain: unpleasant feeling or discomfort that occurs whenever you say it does.
- C. common side effect of cancer and treatment
- D. can last for months or years after treatment completed

## VIII. Overview of Pain

- A. Different ways to describe pain
  - 1. location
  - 2. quality
  - 3. Chronic vs. acute
    - a) break thru pain
  - 4. (ask pt what type of pain she is having)
  
- B. Different causes of pain in breast cancer (page 2 of your workbook)
  - 1. spread of cancer- NOT usually what it is causing pain
  - 2. surgical
    - a) incisional
    - b) phantom limb pain
    - c) posture/positioning
    - d) exercises to reduce pain (tip Sheet available entitled stretching and strengthening exercises)
  - 3. lymphedema (page 3)
    - a) definition
    - b) symptoms

- c) Tip Sheet available
- 4. Pain after radiation
  - a) Shooting Pain

#### C. Medications for Pain

- 1. Over the counter vs. prescription
- 2. Side effects: nausea constipation drowsiness
  - a) Tip Sheet available
- 3. Addiction vs. physical dependence (page 5) vs. med tolerance
- 4. Common misconceptions about pain med
  - a) If take now won't be strong enough later
  - b) If wait won't take as much won't get addicted.

#### D. Non drug methods of Pain relief

- 1. good for mild to moderate pain or to help during that 20 minute s or so it takes for your pain medicine to kick in
- 2. Heat cold
- 3. Distraction
- 4. Massage
- 5. Relaxation
- 6. Tip Sheet available

### IX. Understanding your Pain (page 6 of the work book)

- A. Self evaluation Questions (show them the list- go over a few questions with them and ask them to answer them for themselves during the week.)
- B. Keep diary

## X. Communicating about Pain

- A. Scale 0-10
- B. Family
- C. Oncology team
  - 1. may change medication
  - 2. may indicate need for testing
  - 3. may be able to relieve fears that Cancer is spreading

## XI. Review of Your Pain

- A. What are your problems with pain
- B. Current treatments
- C. How are they working
- D. Suggested treatments/Tip sheets

## XII. Homework

- A. Go over pages with patient
  - B. Practice the suggestions on the tip sheets
  - C. Feel free to jot down any questions or comments you may have in here, so we can go over them next week.
- 
- Before leaving for the day, ask for questions about the materials. Remind the subject to review the written information, listen to the tape and try some of the tips on the tip sheets.
  - Set appointment for next visit.

## **BCEI – 2**

### **Supplies:**

1. Research Nurse's script and binder
2. Pens
3. Business cards
4. Tape recorder and extra batteries to tape the session
5. Blank tape
6. Directions
7. Patient file
8. Second two modules
9. Audiotape: Emotions and New You
10. Tip sheets
11. Highlighter

### **Guidelines and Talking Points**

- Set up tape recorder and verify that subject still wants to participate in the study
- Ask if there are any questions about participating in the study or about the study materials from the previous BCEI intervention
- Review homework, encourage subject to try some of the tips on the tip sheets, give examples of some that have worked for other subjects
- Give overview of second BCEI intervention
- Provide materials for second BCEI intervention



## **Outline of essential information – Emotions & New You modules**

### **I. Introduction Emotions**

#### **A. Range of emotions that can occur**

1. Fear/anxiety
2. Joy at completion of treatment

What emotions have you experienced since you've completed your treatment

### **II. Overview of Emotions**

#### **A. Symptoms of Anxiety**

1. Feeling nervous
2. Overwhelmed
3. Difficulty concentrating
4. Sleeplessness
5. Teary, weepy
6. Irritable
7. Severe cases (panic attacks): tachycardia /SOB
  - a) Not as common.
8. Have you experienced any symptoms of anxiety?

#### **B. Ways to manage anxiety**

1. Reestablish old routines/ start new routines
2. Reconnect with friends and family
3. Returning to work
  - a) [If appropriate] When did you return to work?

#### **C. Fear**

1. Another common emotion women experience is Fear of recurrence
  - a) Definition of recurrence
    - (1) Local
    - (2) Regional

(3) Metastasis

b) Natural to have this fear after experiencing a life threatening disease

(1) Often triggered by anniversary dates/follow up visits

c) Stage one and stage two have a very low risk for recurrence

d) Intrusive thoughts

2. Uncertainty about the future

a) Not feeling sure about future plans

(1) Will you be there for children/grandchildren?

(2) Trip?

(3) Work projects?

b) Hypervigilance about health (pg. 4)

(1) Keep good records

(2) Educate self on reasons for tests /risk of recurrence

(3) Write down questions

(4) Stay informed on new developments

(5) Know the warning signs of recurrence

(a) Unexplained pain

(b) Lump

3. Fear of abandonment (only discuss if appropriate)

a) Breast cancer doesn't create marital problems/ enhances them

b) Every relationship is different

c) Do you have any concerns in this area?

D. Ways to manage fears (can be found in section on fears of recurrence page 2)

1. Thought stopping strategies

2. Relaxation

3. Meditation
4. Journaling
5. Stay in the moment
6. Exercise
7. Medications (prescription)

III. Understanding your emotions (page 5)

A. Self evaluation Question

IV. Communicating about Emotions

A. Family

1. Have same fears/don't try to protect them
2. Do not have whole laundry list to go through at one time
3. Need to have a confidante

B. Oncology team

1. Be sure to tell them what you've tried to manage fear
2. Let them know what you do want and don't want to know
3. May be able to help you differentiate between legitimate fears and irrational fears
4. If severe
  - a) may prescribe medication
  - b) may refer for counseling

V. Review of Your Emotions

A. What are your problems with emotions

B. Current treatments

C. How are they working

D. Suggested treatments/Tip sheets

## Outline of Essential information for the New You

### VI. Introduction New You

#### A. Changed forever

1. physical changes
2. relationship changes that affect your family friends and work

### VII. Overview of New You

#### A. Physical changes

##### 1. Surgical changes

- a) scars
- b) reconstruction/prosthesis
- c) lymphedema
- d) numbness
- e) are any of these a concern for you?

##### 2. Radiation changes

- a) markings
- b) loss sensation
- c) shooting pains
- d) are any of these a concern for you?

##### 3. Chemotherapy induced menopause

- a) hot flashes
- b) vaginal dryness
- c) osteoporosis
- d) heart disease
- e) are any of these a concern for you?

#### B. Psychological changes

##### 1. Grief/loss

- a) normal

##### 2. Body Image

- a) definition way you see self based on body i.e. no longer feminine due to loss of breast, clumsy due to swelling/loss of feeling
- b) example: anorexic teenager

3. Intimacy

- a) afraid to open up/share fears
  - (1) Distant from family/friends- they may be afraid to bring up the subject
- b) changes in roles
  - Have you experienced any role conflicts?
- c) afraid to share physical changes with your husband/ children

4. Sexuality (just briefly review if pt not sexually active)

- a) feeling undesirable
- b) fear of rejection
  - (1) Loss of breast not as important as survival
- c) partners fears
  - (1) Pain
  - (2) You'll say when you are ready
- d) start slow and be comfortable with one another
- e) keep communication open
- f) option of counseling

VIII. Understanding the New You (find on page 5)

A. Self evaluation Questions

IX. Communicating about the New You

A. Family

1. Roles

- a) marriage
- b) children
- c) work (be sure they are aware they are under no obligation to tell their employer-it just may be helpful.)

2. Intimacy/sexuality

- a) set aside a time to talk
- b) no laundry lists

B. Oncology team

- 1. Menopausal symptoms
- 2. Prevention of osteoporosis and heart disease
- 3. Oncology team
  - a) May not bring sexuality issues up
  - b) Doesn't mean they won't talk to you about them
  - c) Identify one person-Dr/Nurse/SW

X. Review of New You

- A. What are your problems with the New You
- B. Current treatments
- C. How are they working
- D. Suggested treatments/Tip sheets

XI. Homework

- A. Go over pages with patient
  - B. Instruct them to write down any questions or comments they may have regarding the information they received.
- 
- Before leaving for the day, ask for questions about the materials. Remind the subject to review the written information, listen to the tape and try some of the tips on the tip sheets.
  - Set appointment for next visit.

## **BCEI – 3**

### **Supplies:**

1. Research Nurse's script and binder
2. Pens
3. Business cards
4. Tape recorder and extra batteries to tape the session
5. Blank tape
6. Directions
7. Patient file
8. Last module
9. Audiotape: Soul and Body
10. Tip sheets
11. Highlighter

### **Guidelines and talking points:**

- Set up tape recorder and verify that subject still wants to participate in the study
- Ask if there are any questions about participating in the study or about the study materials from the previous BCEI intervention
- Review homework, encourage subject to try some of the tips on the tip sheets, give examples of some that have worked for other subjects
- Give overview of third BCEI intervention
- Provide materials for third BCEI intervention

## Outline of essential information - Soul and Body module

### I. Introduction Body and Soul

#### A. Definition of spirituality: different for different people

1. Traditionally-Faith
2. Meaning and purpose
3. Sense of love and belonging
4. Hope

#### B. Common for women to question these issues after life threatening disease

1. You have come through treatment
2. Found strength you didn't know you had

#### C. Can be a long process

1. May take months
2. Issue that women deal with especially in the first year

### II. Overview of Spirituality

#### A. Meaning and Purpose in Life (page 2)

1. Define: Many women ask why am I here, why did I survive?
2. Ponder important things in life
  - a) establish priorities
  - b) family friends and what they mean to you
  - c) work and its meaning/volunteer work
  - d) social issues
  - e) breast cancer advocacy – can be as simple as telling other people about our breast cancer and how you've gotten thru it

#### B. Sense of Love and Belonging

1. Sometimes women feel isolated
2. Talk to family/friends
  - a) awkward moments
  - b) expect them
  - c) broach the subject
  - d) don't need to talk about it if you don't want to
3. Spend time enjoying family and friends
4. Support group



### C. Hope (page 3)

1. Define: positive expectation about the future, having goals for yourself
  - a) some feel loss of hope occasionally
  - b) this is normal
2. How hopeful are you for the future?
3. Ways to foster hope
  - a) Relationships
    - (1) family
    - (2) friends
    - (3) work
    - (4) support groups- pt advocacy
  - b) Live day to day
    - (1) focus on today
    - (2) do not allow intrusive thoughts
  - c) Appreciating nature
  - d) Realistically face fear

### D. Faith/religious activities (page 2)-Do you have a particular faith that you practice?

1. Women who have specific religious practices may continue them.
  - a) prayer,
  - b) meditation,
  - c) reading scripture
  - d) attending place of worship (church synagogue...)
2. Others may have new interest in religion
  - a) explore with Friends neighbors
3. Some may be angry at God/question God
  - a) common to have these feelings
  - b) talk to spiritual leader

## III. Understanding your Soul and Body (page 4)

### A. Self evaluation Questions

IV. Communicating about your soul and Body

A. Some people are uncomfortable discussing spirituality

1. Find someone you can talk to
  - a) family member
  - b) confidant/friend
  - c) pastor/priest
  - d) another breast cancer survivor

B. Oncology team

1. May not bring up the topic, but may be interested in your perspective
2. May refer you to support group or counselor

V. Review of Your Soul and Body

- A. What are your concerns with spirituality
- B. Current treatments
- C. How are they working
- D. I would like to suggest some treatments/Tip sheets

VI. Homework

- A. Go over pages with participant
  - B. While you are going over the chapter and reading your homework feel free to write down any questions you may have. Then you can call and ask me or wait until my follow-up phone call the following month.
- Before leaving for the day, ask for questions about the materials. Remind the subject to review the written information, listen to the tape and try some of the tips on the tip sheets.
  - Remind subject that you will be talking with her next month and review the Intervention Log goals
  - Review procedures for the remainder of the study.

## Telephone Reinforcement- Months 2, 4 and 5

### Purpose

The purpose of these guidelines is to facilitate the Research Nurse's ability to consistently deliver the telephone reinforcement and obtain the data for the intervention log.

### Objective

To implement the BCEI telephone reinforcement procedure in a standardized manner.

### Time Frame

Reinforcement phone calls will occur during the second, fourth and fifth months of the study. Prior to initiating the phone call, pull out the subject's file and review her progress notes as well as which tip sheets were given (if in experimental group). Write NA next to any questions on the intervention log that do not apply to the particular subject to facilitate a quick completion of the log when you have the patient on the phone. Not all questions will apply to each patient. Several situations will be reflected in the intervention log answers:

- No problem and No tip sheet given
- No problem but given tip sheet for information only
- Problem and given tip sheet

Indicate "NA" if there was no problem and no tip sheet given. If tip sheet was given for information only, mark the shaded "I have no problem..." answer and then ask how often they reviewed it. If they have not used the tips, you cannot evaluate its effectiveness, indicate "NA" to the scale. Throughout the study, subjects may develop a new problem or concern. If this occurs, and they have started using the tip sheet, rate the effectiveness of the tips. Indicate on the intervention log that it is a new problem. Patient may also request at any time, any of the tip sheets. These will be available at each visit. The research nurses will mark the review sheets and future intervention logs accordingly.

### Guidelines for telephone reinforcement Month 2 - Experimental Subject

- Introduction
- Ask about any issues that were of concern for the subject at the last visit
- Review purpose of telephone reinforcement and explain what you will be asking
- Acknowledge that several tips sheets were given, but may not have been for "problems", but for informational purposed
- Explain rationale for asking about all of the tip sheets
- Remind the subject to answer honestly

**Key:** If the patient did not read the materials or listen to the tapes, ask why in a non-judging manner.

Define answers as follows:

- "a few times" means **1-3 times**
- "several times" means **4-9 times**
- "almost always" means **10 or more times**
- 

Check the "N/A" box if they did not have the problem or take the tips.

If they have not used any of the tip sheets, encourage them to try them this month if needed.

Indicate if they have developed any new problems and are now using the tip sheets

- Before telephone reinforcement is completed, try to set up appointment for Month 3 data collection or arrange to call the subject in a few weeks to set this up. Be sure date set is at least 60 and not more than 90 days after the first data collection date.)
- Ask if there are any questions

### **Guidelines for telephone reinforcement Month 2 - Wait Control Subject**

- Introduction
- Ask about any issues that were of concern for the subject.
- Set up appointment for Month 3 data collection or arrange to call the subject in a few weeks to set up the appointment. Be sure date set is at least 60 and not more than 90 days after the first data collection date.)
- Ask if they have any questions or concerns about participating in the study

### **Guidelines for telephone reinforcement Month 4 - Experimental Subject**

- Introduction
- Ask about any issues that were of concern for the subject at the last visit
- Review purpose of telephone reinforcement and explain what you will be asking
- Acknowledge that several tips sheets were given, but may not have been for “problems”, but for informational purposes
- Explain rationale for asking about all of the tip sheets
- Remind the subject to answer honestly

**Key:** If the patient did not read the materials or listen to the tapes, ask why in a non-judging manner. Define answers as follows:

- “a few times” means **1-3 times**
- “several times” means **4-9 times**
- “almost always” means **10 or more times**
- 

Check the “N/A” box if they did not have the problem or take the tips.

If they have not used any of the tip sheets, encourage them to try them this month if needed.

Indicate if they have developed any new problems and are now using the tip sheets

- Before telephone reinforcement is completed, remind subject that you will be contacting her next month to go over the Intervention Log
- Ask if there are any questions

### **Guidelines for telephone reinforcement Month 4 - Wait Control Subject**

- Introduction
- Ask about any issues that were of concern for the subject.
- Remind subject that you will be calling again next month
- Ask if they have any questions or concerns about participating in the study

### **Guidelines for telephone reinforcement Month 5 - Experimental Subject**

- Introduction
- Ask about any issues that were of concern for the subject at the last visit
- Review purpose of telephone reinforcement and explain what you will be asking
- Acknowledge that several tips sheets were given, but may not have been for “problems”, but for informational purposes
- Explain rationale for asking about all of the tip sheets
- Remind the subject to answer honestly

**Key:** If the patient did not read the materials or listen to the tapes, ask why in a non-judging manner. Define answers as follows:

- “**a few times**” means **1-3 times**
- “**several times**” means **4-9 times**
- “**almost always**” means **10 or more times**
- 

Check the “N/A” box if they did not have the problem or take the tips.  
If they have not used any of the tip sheets, encourage them to try them this month if needed.  
Indicate if they have developed any new problems and are now using the tip sheets

- Before telephone reinforcement is completed, Try to make an appointment for the final data collection
- Ask if there are any questions

### **Guidelines for telephone reinforcement Month 5 - Wait Control Subject**

- Introduction
- Ask about any issues that were of concern for the subject.
- Set up appointment for Month 6 data collection or arrange to call the subject in a few weeks to set up the appointment.
- Ask if they have any questions or concerns about participating in the study