

FOCUS:

Family-based Interventions for Men with Prostate Cancer and their Spouses/Partners

- F** family involvement
- O** optimistic attitude
- C** coping effectiveness
- U** uncertainty reduction
- S** symptom management

Intervention Protocol Manual

I. GOALS OF THE PROGRAM

- Family Involvement:* To encourage active involvement of men and their spouses/partners in a planned program of care.
- Optimistic Attitude:* To assist men and their spouses/partners to maintain a positive outlook as they live with the illness and consider their future.
- Coping Effectiveness:* To foster the use of active, problem-focused coping strategies by men and their spouses/partners to manage the stressful impact of the illness and/or treatments.
- Uncertainty Reduction:* To assist men and their spouses/partners to obtain information that will reduce their uncertainty about the illness and/or treatments.
- Symptom Management:* To teach men and their spouses/partners ways to manage reactions and side effects associated with the illness, treatments, and adjustment.

II. THERAPEUTIC FOCUS OF PROGRAM SESSIONS

- Scope:* The scope of the program will be on “here and now” issues related to promoting men’s and spouses’/partners’ quality of life.
- Mode:* The mode of intervention will consist of education, resource provision, and supportive counseling techniques.
- Strategy:* The intervention strategy will be a time-limited, family-based, problem-solving intervention approach.
- Focus:* Each session will contain uniform core program content as well as be flexible to address the specific concerns of men and their spouses/partners.
- Priorities:* Some content areas will be given higher priority within a particular session. However, all content specified will be covered to some extent and checked off when completed.
- Continuity:* The continuity between sessions will be enhanced by having men and their spouses/partners meet with the same intervention staff for all of the sessions.

FOCUS: INTERVENTION PROTOCOL

Patient's Name

Spouse's/Partner's Name

Intervention Nurse's Name

KEY: ✓ = done
 NA = not applicable
 O = not done

SESSION A: Face-to-Face Meeting

Date _____

I. Overview

- A. *Type of session:* The first session is a 1 1/2 hour, face-to-face interview that will be conducted jointly with a patient and his spouse/partner.
- B. *Location and timing of session:* To insure the participation by as many couples as possible, the session will take place in the privacy of the patient's home or in a private office in the cancer center. Note who attends and where session occurs.

The first session will take place during week 0 of the intervention.

Give "Reminder Card" at end of first session with dates of next phone contact and face-to-face interview.

II. Objectives, Checklist, Specific Session Content

A. Family involvement:

1. _____ Establish a therapeutic alliance with the man and his spouse/partner.
 - a. Discuss purpose of Focus Program (review pamphlet):
 1. Cancer effects not only the patient, but the patient's significant others.
 2. Sessions are designed to meet the patient's and the spouse's/partner's need for hope, support, education, and coping strategies to deal with the treatment of cancer.
 3. Tell patient and spouse/partner that our goal is to help them not judge them on their reactions to cancer.
 4. Explain that intervention nurse does not see patient's or spouse's/partner's responses to questionnaires used for data collection.

- b. Discuss meeting times, length and location of sessions:
 - 1. Appointments will be scheduled at a convenient time and at an agreed upon location.
 - 2. Sessions will include 3 face to face appointments (lasting 1½ hours each) and 2 phone appointments (lasting 15-30 minutes each)
 - 3. It is important that both patient and spouse/partner participate in each session.
 - c. Discuss intervention nurse's role with family.
 - d. Obtain background information such as medical history related to cancer and family composition. Assess couple's communication.
2. ____ Discuss importance of patient's and spouse's/partner's involvement in plan of care.
- a. Spouse's/partner's role is important; they need to be educated about patient's illness.
 - b. Spouse/partner can learn how to help and support patient.
 - c. Spouse/partner needs to have a sense of control over events related to the patient's illness.
3. ____ Discuss importance of mutual support within dyad at this time:
- a. Patients and spouses/partners can help and support each other and work as a team in coping with the illness.
 - b. Encourage patient and spouse/partner to identify and discuss personal and family strengths that may help couple adapt to cancer.
 - c. Give couple "Taking Time" booklet (NCI).
4. ____ Ask how each is coping with the impact of the illness. Encourage both patient and spouse/partner to openly share their feelings and concerns related to the illness.
- a. Ask how illness has affected family relationships.
 - b. Ask how well dyad and extended family are able to communicate with one another.

COMMENTS:

____ % on "F"

B. Optimistic attitude:

1. ____ Assess current outlook about illness.
 - a. Do optimism assessment.
 1. Discuss feelings of patient and spouse/partner.
 - a. *For recently diagnosed patient*, how did you feel when you learned you or your spouse/partner had cancer?
 - b. *For patient with rising PSA*, how did you feel when you learned your or your spouse's/partner's PSA was changing?
 - c. *For patient with advanced or metastatic disease*, how did you feel when you learned your or your spouse's/partner's cancer returned or had spread?
 2. On a scale of 1-10, how would you rate your outlook?
 - a. Patient's rating: _____
 - b. Partner's rating: _____
 3. Is this your usual outlook about things?
 4. What are your sources of hope?
 5. Give optimism magnet.
2. ____ Encourage ventilation of feelings and worries.
 - a. Emphasize the importance of sharing feelings/worries so they can be addressed.
3. ____ Introduce importance and benefits of optimism. Offer general tips to develop/maintain a more positive outlook
 - a. Help couple identify appropriate goals
 - b. Discuss ways to help them increase control in their lives
 - c. Identify assets (personal / family)
 - d. Discuss reframing experiences in more positive light, ask what positive things have come from your cancer experience?
 - e. Focus on small joys
 - f. Discuss that hope is contagious

COMMENTS:

_____ % on "O"

C. Coping effectiveness:

1. ____ Assess effectiveness of current coping strategies.
 - a. Teach about benefits of active vs. passive coping strategies
 - Active (effective/healthy): Problem-solving, seeking help, finding support.
 - Passive (less effective/unhealthy): Use of alcohol, distancing from partner, total denial.
2. ____ Offer use of relaxation tape-“Letting Go of Stress”
 - a. Record if given tape_____
3. ____ *For patients with newly diagnosed/localized disease,* offer dyad “Facing Forward” booklet (NCI)
4. ____ *For patients dealing with a rising PSA or advanced/metastatic disease,* offer dyad the booklet, “When Cancer Recurs.” Point out use of coping strategies on Pages 24-29.

COMMENTS:

_____% on “C”

D. Uncertainty reduction:

1. ____ Assess knowledge deficits and provide factual information about illness (as needed).
 - If needed, give pamphlet-Prostate Cancer: “Treatment Guidelines for Patients” (ACS).
2. ____ Clarify information on patient’s specific treatment including chemotherapy (eg. estramustine, etoposide, paclitaxel), radiation, and hormonal (eg. leuprolide, goserelin, flutamide, bicalutamide) therapies:
 - a. Name/classification of drugs, side effects, when to notify doctor, etc.
 - b. Give handout and/or pamphlet on each drug or treatment.
 - c. If applicable, give pamphlet “Chemotherapy and you” (NCI).
3. ____ Discuss and normalize typical emotional and physical reactions that patients and spouses/partners may experience at this time.
 - a. Fear, sadness or anger about having cancer or that the disease has returned.
 - b. Feelings of uncertainty and anxiety related to fears about future or death (allow ventilation).
 - c. Fatigue related to emotional upheaval.

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4. _____ Give participants the intervention staffs phone number and encourage them to call if any questions arise before next session. (Business card on back of FOCUS pamphlet)
5. _____ If needed, help patient/spouse/partner seek out information ‘from health professionals:
- a. Encourage and/or give permission for patient/spouse/partner to call doctor’s office for needed information.
 - b. Remind patient/spouse/partner that doing so is not a “bother” but an appropriate way to get questions answered.
 - c. Remind them to ask to speak directly to a nurse-not to ask questions of the receptionist.
 - d. Encourage them to utilize resource center at Cancer Center and/or resource center staff for additional information as needed. Support seeking information from other sources including reading books, talking with other survivors and exploring prostate cancer internet sites. Discuss importance of critically evaluating information since all sources may not be reliable.
 - e. Encourage them to be assertive when seeking answers or information from health professionals. Role-play assertive techniques if needed.

COMMENTS:

_____ % on “U”

E. Symptom Management:

1. ____ Assess experiences with prior treatments and associated symptoms.
2. ____ Clarify any myths participants may have about treatments and/or disease.
3. ____ Discuss strategies to manage fatigue, depression, and emotional reactions.
 - a. Give symptom management card on Emotional Reactions to all patients/spouses/partners
4. ____ Give symptom management cards as needed

Examples of common symptoms/side effects related to treatments:

Prostatectomy: Urinary Incontinence, Sexual Concerns

Radiation: Urinary Incontinence, Urinary Problems after Radiation, Bowel Problems after Radiation, Fatigue, Sexual Concerns, Skin Changes

Hormone: Hormone Changes, Sexual Concerns, Weight Gain

Chemotherapy: Appetite Problems, Fatigue, Hair Loss, Infection (lowered WBC), Nausea and Vomiting

- a. List which cards were given

COMMENTS:

_____ % on "S"

FIRST SESSION SUMMARY/FUTURE ISSUES:

Setting: (1) ____ home (2) ____ clinic (3) ____ other (specify)_____

Length of session in minutes: _____

Intervention Nurse's Evaluation:

					Dyad's Need for Intervention				
Low		Med		High					
1	2	3	4	5					

SESSION B: Telephone Follow-up

Date _____

I. Overview

- A. *Type of session:* The second session is a 15-30 minute phone session that will be conducted sequentially, first with the man and then with his spouse/partner, or both may be on the phone simultaneously if a phone extension is available.

This session is considered to be a “booster” session because content from the previous session will be reinforced; very little new content will be introduced during the follow-up phone call.

The session will provide an ongoing link between the participants and the intervention nurse. The nurse will assist participants to problem-solve any new issues that may have occurred since the last visit.

- B. *Location and timing of session:* This session will take place by phone during week 2-3 of intervention.

II. Objectives, Checklist, Specific Session Content

Initial assessment: Ask these three questions of dyad. If there are no problems, concerns or questions, phone session may be abbreviated.

1. How is life going; how are you and your spouse/partner doing?
2. Have there been any changes concerning your cancer?
3. Do you have any questions?

*If issues are raised, discuss the FOCUS topics in more depth with the dyad.

A. Family Involvement:

1. _____ Assess how the couple is managing at this time.
2. _____ Problem-solve with them to work through any difficulties that may have arisen.

COMMENTS:

_____ % on “F”

B. Optimistic Attitude:

1. ____ Ask about dyad's outlook (e.g. "How are your spirits?")
2. ____ Reinforce accomplishments/activities (i.e., attending family function, going out to dinner, maintaining work, etc.)
3. ____ Encourage continuation of activities that will enable them to maintain a positive attitude.

COMMENTS: _____ % on "O"

C. Coping Effectiveness:

1. ____ Encourage patient and spouse/partner to identify stress management activities that they believe are feasible for their lifestyles.
2. ____ Reinforce active rather than passive coping strategies.

COMMENTS: _____ % on "C"

D. Uncertainty Reduction:

1. ____ Provide information as needed.
2. ____ Encourage participants to call clinician or FOCUS nurse if they have questions.

COMMENTS: _____ % on "U"

E. Symptom Management

1. _____ Problem-solve any difficulties with symptom management. Encourage reporting of symptom difficulties to provider.
2. _____ Provide positive feedback for attempts to manage symptoms.

COMMENTS:

_____ % on "S"

SECOND SESSION SUMMARY/FUTURE ISSUES:

Total length of phone session in minutes: _____

(If separate phone calls: minutes with patient _____ and minutes with partner _____)

SESSION C: Face-to-Face Meeting

Date _____

I. Overview

A. Type of session: The third session is a 1-1/2-hour, face-to-face interview that will be conducted jointly with the man and his spouse/partner.

B. Location and timing of session: This session will take place in the patient's home or in the cancer center.

The third session will take place during week 4-6 of the intervention.

Give "Reminder Card" at end of session with dates of next phone contact and face-to-face interview.

II. Objectives, Checklist, Specific Session Content

A. Family involvement:

1. _____ Assess patient's and spouse's/partner's current response to cancer.
 - a. Assess response to recently diagnosed disease, rising PSA or advanced disease as applicable.
 - b. Also, assess children or extended family members' response
 - c. Assess concern re: past/future family history of prostate cancer. Educate re: risk for sons and strategies to manage

2. _____ Acknowledge the ways that couple have helped one another (mutual support) since the last face-to-face session.
 - a. Identify strengths of couple/family.

3. _____ Assess availability and quality of support including outside sources.
 - a. Ask if patient or spouse/partner have any unmet needs.
 - b. Discuss and possibly negotiate a contract between couple to address these needs.

4. _____ Reinforce continued spouse/partner involvement in plan of care.
 - a. Offer option to include children / other family members in final face to face session.

5. _____ Promote communication within dyad and with other family members.
 - a. If needed, teach effective communication skills (use of "I" statements; honest sharing of feelings and concerns; use of non-verbal communication such as holding hands, eye contact, body language, touch; validating messages; restatement; clarification, etc.)
 - b. If needed, give handout "10 commandments of Good Listening."

COMMENTS:

_____ % on "F"

B. Optimistic attitude:

1. ____ Assess outlook (e.g. “How are your spirits?”, “How are you feeling about your future?”
“Are you having any troubles maintaining a positive attitude?”)
2. ____ Explore any concerns or fears that have arisen since last session.
3. ____ Assist man and spouse/partner to mutually discuss and problem solve fears.
4. ____ Reinforce use of optimism strategies discussed in previous session.
 - a. Optimism handout (tailor brochure to couple’s ethnicity): “Fostering An Optimistic Outlook” - Ask couple to read and choose strategies they would be able to use.

COMMENTS:

____ % on “O”

C. Coping effectiveness:

1. ____ Teach stress management techniques (i.e., exercise, relaxation techniques, keeping a journal).
 - a. Help participants to identify which stress management techniques would be the most useful/realistic for them.
 - b. Offer relaxation tape. If already using tape, assess effectiveness.
 1. Is patient using tape? Yes No If so, how often? _____
 2. Is partner using tape? Yes No If so, how often? _____
2. ____ Review active versus passive coping strategies.
 - a. Encourage use of strategies which best suit patient’s/spouse’s/partner’s styles to manage stress associated with illness/treatment.

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- 3.____ Discuss healthy living strategies for both patient and spouse/partner.
- a. Encourage proper nutrition
Give nutrition pamphlet if needed (Eating Hints for Cancer Patients – NCI).
 - b. Discuss exercise habits.
Encourage couple to plan regular exercise (such as “Rhythmic Walking,” give handout if interested) after consulting with MD.
 - c. Promote adequate rest
Explore sleep enhancing strategies, use of naps, rest periods.
 - d. Discuss conserving energy
Pacing self, sitting instead of standing, prioritizing activities.

COMMENTS:

_____ % on “C”

D. Uncertainty reduction:

- 1.____ Elicit questions or needs for additional information.
- 2.____ Review ways to obtain needed information. If needed, review assertive techniques.
- 3.____ Discuss ongoing emotional reaction / concerns that may arise about future.
 - a. Assess interest in advanced directives/wills.
 - b. Offer “Planning for Your Peace of Mind” booklet (State of Michigan).
- 4.____ Encourage participants to contact intervention staff if questions arise prior to next session.

COMMENTS:

_____ % on “U”

E. Symptom management:

1. ____ Follow up with patient about side effects he's experiencing.
 - a. Ask if management strategies were effective.
 - b. Assess if new side effects have occurred.

2. ____ Gently ask whether patient has experienced symptoms such as sexual difficulties or urinary problems. Assess willingness to discuss these issues.
 - a. Ask: Prostate cancer can interrupt a couple's normal sexual routines. Have the two of you found this to be a problem?
 - b. Assess importance of sexual/urinary symptoms to patient's/spouse's/partner's quality of life.
 1. Dispel any myths couple may have including the notions that prostate cancer is contagious or that having sexual relations will increase PSA.
 2. Ask female partners if they are having troubles with menopausal symptoms such as vaginal dryness, which may affect their interest and ability to engage in intercourse. If needed, give card with information about vaginal lubricants.
 - c. Offer symptom management card "Sexual Concerns" and booklet "Sexuality and Cancer: For the Man Who Has Cancer and His Partner" (ACS)
 - d. Encourage couple to discuss openly their feelings about changes in their sexual relationship and ways to problem-solve any issues they have.
 - e. Give permission to discuss sexual and urinary concerns with oncology specialist.
 - f. Offer information on Kegel exercises and skin care related to incontinence as needed.

3. ____ Discuss fears, worries and anxiety related to monitoring PSA and possible increasing levels

4. ____ Give participants a copy of the symptom management treatment cards that is specific to his particular treatment.
 - a. List which cards were given

 - b. If symptom management cards were given in previous session, were they effective?

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- 5. _____ Give pamphlets on management of pain, if needed.
 "Understanding Cancer Pain" (NCI).
- 6. _____ Ask *spouse/partner* if she is experiencing any emotional or physical symptoms.
 - a. Discuss need for spouse/partner to address her own physical needs.
 - b. Encourage spouse/partner to seek regular preventative health care.
 - c. Encourage spouse/partner to report symptoms/physical problems to health care provider.

COMMENTS:

_____ % on "S"

THIRD SESSION SUMMARY/FUTURE ISSUES:

Setting: (1) _____ home (2) _____ clinic (3) _____ other (specify) _____
 Length of session in minutes: _____

Intervention Nurse's Evaluation:

					Dyad's Need for Intervention				
Low		Med		High					
1	2	3	4	5					

SESSION D: Telephone Follow-up

Date _____

I. Overview

- A. Type of session:* The fourth session is a 15-30 minute phone session that will be conducted with both the man and his spouse/partner.

This session, like session B, is considered to be a ‘booster’ session because content from previous sessions will be reinforced; little new content will be introduced during this follow-up phone call.

The session will provide an ongoing link between the participants and the intervention nurse. The nurse will assist participants to problem-solve any new issues that may have occurred since the last contact.

- B. Location and timing of session:* This session will take place by phone during week 6-9 of the intervention.

II. Objectives, Checklist, Specific Session Content

Initial assessment: May ask these three questions of dyad. If there are no problems, concerns or questions, phone session may be abbreviated.

1. How is life going; how are you and your spouse/partner doing?
2. Have there been any changes concerning your cancer?
3. Do you have any questions?
4. What would you like to cover in our final session?

*If issues are raised, discuss the FOCUS topics in more depth with the dyad.

A. Family Involvement:

1. _____ Assess how the patient/spouse/partner is managing at this time.
2. _____ Reinforce the combined efforts of couple.

COMMENTS:

_____ % on “F”

B. Optimistic Attitude:

- 1. ____ Encourage participants to consider positive things that can occur as a result of illness (i.e., more focus on quality time).
- 2. ____ Encourage continuation of optimism strategies.
 - a. Which ones are particularly helpful to them?

COMMENTS: _____ % on "O"

C. Coping Effectiveness:

- 1. ____ Reinforce activities that promote stress reduction (i.e., exercise, relaxation activities, making time for self).
- 2. ____ Provide support for active coping activities that participants have engaged in recently.

COMMENTS: _____ % on "C"

D. Uncertainty Reduction:

- 1. ____ Elicit questions or need for information. Review ways to obtain needed information.
- 2. ____ Encourage participants to call if they have questions.

COMMENTS: _____ % on "U"

E. Symptom Management:

- 1. ____ Problem-solve any difficulties that have occurred with symptom management.
- 2. ____ Reinforce attempts to manage symptoms.
- 3. ____ Encourage active reporting and follow-up of symptoms with health care provider.

COMMENTS: _____ % on "S"

FOURTH SESSION SUMMARY/FUTURE ISSUES:

Total length of phone session in minutes: _____
(If separate phone calls: minutes with patient _____ and minutes with partner _____)

SESSION E: Final Face-to-Face Meeting

Date _____

I. Overview

- A. Type of session:* The fifth session is a 1-1/2-hour face-to-face interview that will be conducted jointly with the man and his spouse/partner.
- B. Location and timing of session:* This session will take place in the patient's home or in the cancer center.

The fifth session will take place during week 8-12 of the intervention.

At the end of session, remind couple that Data Collection Nurse will be calling soon to schedule an appointment for completing the next set of questionnaires.

II. Objectives, Checklist, Specific Session Content

A. Family Involvement:

1. ____ Discuss family issues or problems that may have arisen in response to the illness or treatment.
 - a. Discuss ways to inform adult children or young children (including grandchildren) about illness, if needed.
 1. Refer couple to books that may be helpful (eg "When a Parent has Cancer" by Wendy Harpham or "How to Help Children through a Parent's Serious Illness" by Kathleen McCue).
 2. Give pamphlet on children's response, if appropriate. [Handout: "Helping Your Children Cope With Your Cancer"]
2. ____ Discuss long-term strategies for handling family difficulties that may arise associated with the illness, encourage ongoing open communication.
3. ____ Reinforce couple's attempts to work together as a "team," identify gains couple have made.
4. ____ Debrief with patient/spouse/partner since this is their last contact with the intervention nurse.
5. ____ Discuss with participants the name of a health professional associated with the oncology clinic or physician's office that they can call if they have questions.

COMMENTS:

_____ % on "F"

B. Optimistic Attitude

1. _____ Assist participants with realistic goal-setting.
2. _____ Reinforce continued daily use of optimism strategies.
3. _____ Assist participants to identify activities that they can do that have a positive or meaningful focus.

COMMENTS:

_____ % on "O"

C. Coping Effectiveness:

1. _____ Discuss effectiveness of stress management techniques learned in prior sessions.
2. _____ Reinforce active coping strategies they may have used since last session. Discuss importance of daily practicing of stress reduction/active coping strategies.
3. _____ Assess whether using relaxation tape. (Return if not using)
 - a. Is patient using tape? Yes No If so, how often? _____
 - b. Is partner using tape? Yes No If so, how often? _____
4. _____ Discuss availability of community resources to address physical and psychosocial needs (e.g., where to get hair prosthesis).
 - a. Use local referral books as needed/available
 - b. Give referrals to local support groups if needed
 1. May offer phone list of prostate cancer support groups
 2. May offer Man to Man and/or Gilda's Club brochures

COMMENTS:

_____ % on "C"

D. Uncertainty Reduction:

- 1. _____ Provide any factual information as needed
- 2. _____ Review assertive techniques to get questions answered as needed.
- 3. _____ Discuss strategies for “living with uncertainty” (focus on “today”, try to stay optimistic, work on those concerns which you can control and let go of those outside of your control, accept that some uncertainty is part of our lives, etc.)

COMMENTS: _____ % on “U”

E. Symptom Management:

- 1. _____ Review symptom management including any symptoms spouse/partner reported in previous session.
- 2. _____ Discuss ways to manage ‘problematic’ symptoms that may have developed since last session.
- 3. _____ Reinforce participants’ attempts to manage symptoms.
- 4. _____ Assess and validate what is stable or improving regarding symptoms.
- 5. _____ Give symptom management cards, as needed.

COMMENTS: _____ % on “S”

FINAL SESSION SUMMARY:

Setting: (1) _____ home (2) _____ clinic (3) _____ other (specify) _____

Length of session in minutes: _____

Intervention Nurse’s Evaluation:

	Dyad’s Need for Intervention				
	Low		Med		High
	1	2	3	4	5