

PROST-QA APPENDIX 11.3: SSS-Ca

PATIENT SATISFACTION INSTRUMENT

Indicate the answer that best describes your feeling about each aspect of the services you have received. We are interested in your *overall experience during the last year* with care or therapy that you have received related to your cancer therapy or its side effects. By "practitioner" we mean the one or more doctors, clinicians, etc., who have worked with you in your cancer- related care.

What is your overall feeling about the . . .

1. Effect of health care services in helping you deal with your cancer and maintain your well being?
2. Professional knowledge and competence of your main cancer practitioner(s)?
3. Ability of your main cancer practitioner(s) to listen and respond to your concerns or problems?
4. Personal manner of the main cancer practitioner(s) seen?
5. Waiting time between asking to be seen or treated and the appointment given?*
6. Waiting time when you come for an appointment?*
7. Availability of appointment times that fit your schedule?*
8. Effect of cancer treatment in preventing cancer progression or recurrence?
9. How well your confidentiality and rights as an individual have been protected?
10. Quality of cancer care you have received?
11. Availability of information on how to get the most out of the cancer care and related services?*
12. Explanations of specific procedures and treatment approaches used?*
13. Effect of services in helping relieve symptoms or reduce problems?
14. Thoroughness of the main cancer practitioner(s) you have seen?
15. Helpfulness of the information provided about your cancer and its treatment?*
16. In an overall general sense, how satisfied are you with the cancer treatment you have received?

CATI Response options for each of the above items are as follows):

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Completely Satisfied	Very Satisfied	Somewhat Satisfied	Mixed	Somewhat Unsatisfied	Very Unsatisfied	Completely Unsatisfied

*Foot Note: "SSS-Ca and SSS-Ca-Spouse/Partner items 5,6,7,11,12, and 15 (Waiting and Information modules) will not be administered at 12 months and there after, as excessive recall would be required."

PROST-QA APPENDIX 11.4: SSS-Ca Spouse/Partner

PATIENT SATISFACTION INSTRUMENT

Indicate the answer that best describes your feeling about each aspect of the services you have received. We are interested in your *overall experience during the last year* with care or therapy that you have received related to your cancer therapy or its side effects. By "practitioner" we mean the one or more doctors, clinicians, etc., who have worked with you in your cancer- related care.

What is your overall feeling about the . . .

- 1. Effect of health care services in helping your spouse or partner deal with their cancer and maintain well being?**
- 2. Professional knowledge and competence of your spouse or partner's main cancer practitioner(s)?**
- 3. Ability of your spouse or partner's main cancer practitioner(s) to listen and respond to your concerns or problems?**
- 4. Personal manner of the main cancer practitioner(s) seen?**
- 5. Waiting time between asking to be seen or treated and the appointment given?***
- 6. Waiting time when your spouse or partner comes for an appointment?***
- 7. Availability of appointment times that fit your and your partner or spouse's schedule?***
- 8. Effect of cancer treatment in preventing cancer progression or recurrence?**
- 9. How well your confidentiality and rights as a couple have been protected?**
- 10. Quality of cancer care your spouse or partner received?**
- 11. Availability of information on how to get the most out of the cancer care and related services?***
- 12. Explanations of specific procedures and treatment approaches used?***
- 13. Effect of services in helping relieve your spouse or partner's symptoms or reduce problems?***
- 14. Thoroughness of the main cancer practitioner(s) you have seen?**
- 15. Helpfulness of the information provided about your spouse or partner's cancer and its treatment?**
- 16. In an overall general sense, how satisfied are you with the cancer treatment your spouse or partner received?**

(CATI Response options for each of the above items are as follows):

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Completely</i>	<i>Very</i>	<i>Somewhat</i>	<i>Mixed</i>	<i>Somewhat</i>	<i>Very</i>	<i>Completely</i>
<i>Satisfied</i>	<i>Satisfied</i>	<i>Satisfied</i>		<i>Unsatisfied</i>	<i>Unsatisfied</i>	<i>Unsatisfied</i>

*Foot Note: "SSS-Ca and SSS-Ca-Spouse/Partner items 5,6,7,11,12, and 15 (Waiting and Information modules) will not be administered at 12 months and there after, as excessive recall would be required."

PROST-QA APPENDIX 11.5: EPIC Short Form for Partners or Spouses

This questionnaire is designed to help us understand how much the following symptoms have been a problem to the spouses and/or partners of men with prostate cancer.

1. How much has your husband's or partner's **urinary incontinence**, such as urinary leakage or loss of urinary control been a problem for you during the last four weeks?

No problem	1	
Very small problem	2	
Small problem	3	(circle one number)
Moderate problem	4	
Big problem	5	

2. How much has your husband's or partner's **urinary irritation or blockage**, such as frequent urination, pain or burning with urination, urinary urgency, waking up to urinate, blood in the urine, or related difficulties in passing his urine, been a problem for you during the last four weeks?

No problem	1	
Very small problem	2	
Small problem	3	(circle one number)
Moderate problem	4	
Big problem	5	

3. How much has your husband's or partner's **overall urinary function**, such as urinary leakage, incontinence, frequent urination, urinary urgency, urinary burning, urinary bleeding, waking up to urinate, or other urinary difficulties been a problem for you during the last four weeks?

No problem	1	
Very small problem	2	
Small problem	3	(circle one number)
Moderate problem	4	
Big problem	5	

4. How much has your husband's or partner's **bowel habits**, such as rectal urgency, frequent bowel movements, leakage of stool, bloody stool, or painful bowel movements, been a problem for you during the last four weeks?

No problem	1	
Very small problem	2	
Small problem	3	(circle one number)
Moderate problem	4	
Big problem	5	

5. How much has your husband's or partner's **sexual function** such as his degree of sexual desire, the frequency and quality of his erections, or the level of sexual activity, been a problem for you during the last 4 weeks?

No problem	1	
Very small problem	2	
Small problem	3	(circle one number)
Moderate problem	4	
Big problem	5	

6. How much has your husband's or partner's **hormone function and vitality**, such as lack of energy, hot flashes, breast tenderness, weight gain, or mood changes, been a problem for you during the last 4 weeks?

No problem	1	
Very small problem	2	
Small problem	3	(circle one number)

Moderate problem	4
Big problem	5

Caregiver Burden Scale

Caregiver's name: _____ Date: _____

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

	Never	Rarely	Sometimes	Frequently	Nearly always
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0	1	2	3	4
15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Total score: _____

SCORING KEY:

0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.

FIGURE 4. Caregiver Burden Scale. This self-administered 22-item questionnaire assesses the "experience of burden."

Adapted with permission from Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 1980;20:649-55.

Charlson Comorbidity Scoring System (http://touchcalc.com/calculators/cci_js)

Estimating Prognosis for Dialysis Patients

programmed by Stephen Z. Fadem, M.D., FACP, FASN

Age yrs Serum Albumin g/dL

Since the lower limits of albumin for lab are < 3.5 g/dL enter lower limits of albumin (LLA) below

One Point

- ☐ Myocardial infarction (history, not ECG changes only)
- ☐ Congestive heart failure
- ☐ Peripheral disease (includes aortic aneurysm ≥ 6 cm)
- ☐ Cerebrovascular disease: CVA with mild or no residua or TIA
- ☐ Dementia
- ☐ Chronic pulmonary disease
- ☐ Connective tissue disease
- ☐ Peptic ulcer disease
- ☐ Mild liver disease (without portal hypertension, includes chronic hepatitis)
- ☐ Diabetes without end-organ damage (excludes diet-controlled alone)

Two Points

- ☐ Hemiplegia
- ☐ Moderate or severe renal disease
- ☐ Diabetes with end-organ damage (retinopathy, neuropathy, nephropathy, or brittle diabetes)
- ☐ Tumor without metastasis (exclude if > 5 y from diagnosis)
- ☐ Leukemia (acute or chronic)
- ☐ Lymphoma

Three Points

- ☐ Moderate or severe liver disease

Six Points

- ☐ Metastatic solid tumor
- ☐ AIDS (not just HIV positive)

Charlson Comorbidity Index (CCI) Score: 0 Age factored in: NaN. Data not available if CCI less than 2.

COST – FACIT (Version 1)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		Not at all	A little bit	Some- what	Quite a bit	Very much
FT1	I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment.....	0	1	2	3	4
FT2	My out-of-pocket medical expenses are more than I thought they would be	0	1	2	3	4
FT3	I worry about the financial problems I will have in the future as a result of my illness or treatment	0	1	2	3	4
FT4	I feel I have no choice about the amount of money I spend on care	0	1	2	3	4
FT5	I am frustrated that I cannot work or contribute as much as I usually do.....	0	1	2	3	4
FT6	I am satisfied with my current financial situation	0	1	2	3	4
FT7	I am able to meet my monthly expenses	0	1	2	3	4
FT8	I feel financially stressed.....	0	1	2	3	4
FT9	I am concerned about keeping my job and income, including work at home.....	0	1	2	3	4
FT10	My cancer or treatment has reduced my satisfaction with my present financial situation	0	1	2	3	4
FT11	I feel in control of my financial situation	0	1	2	3	4

ID# _____ Day 01 _____ Day 16 _____ Day 30 _____

CAREGIVER QUALITY OF LIFE- CANCER

Below is a list of statements that other people caring for loved ones with cancer have said are important. By circling one number per line, please indicate how true each statement has been for you during the past 7 days.

0	=	Not at all	2	=	Somewhat
1	=	A little bit	3	=	Quite a bit
		4	=		Very much

During the past 7 days:

- | | | | | | | |
|-----|---|---|---|---|---|---|
| 1. | It bothers me that my daily routine is altered. | 0 | 1 | 2 | 3 | 4 |
| 2. | My sleep is less restful. | 0 | 1 | 2 | 3 | 4 |
| 3. | My daily life is imposed upon. | 0 | 1 | 2 | 3 | 4 |
| 4. | I am satisfied with my sex life. | 0 | 1 | 2 | 3 | 4 |
| 5. | It is a challenge to maintain my outside interests. | 0 | 1 | 2 | 3 | 4 |
| 6. | I am under a financial strain. | 0 | 1 | 2 | 3 | 4 |
| 7. | I am concerned about our insurance coverage. | 0 | 1 | 2 | 3 | 4 |
| 8. | My economic future is uncertain. | | 0 | 1 | 2 | 3 |
| 4 | | | | | | |
| 9. | I fear my loved one will die. | 0 | 1 | 2 | 3 | 4 |
| 10. | I have more of a positive outlook on life since my loved one's illness. | 0 | 1 | 2 | 3 | 4 |
| 11. | My level of stress and worries has increased. | 0 | 1 | 2 | 3 | 4 |
| 12. | My sense of spirituality has increased. | 0 | 1 | 2 | 3 | 4 |
| 13. | It bothers me, limiting my focus to day-to-day. | 0 | 1 | 2 | 3 | 4 |
| 14. | I feel sad. | 0 | 1 | 2 | 3 | 4 |
| 15. | I feel under increased mental strain. | 0 | 1 | 2 | 3 | 4 |
| 16. | I get support from my friends and neighbors. | 0 | 1 | 2 | 3 | 4 |
| 17. | I feel guilty. | 0 | 1 | 2 | 3 | 4 |
| 18. | I feel frustrated. | 0 | 1 | 2 | 3 | 4 |

							(OVER ⇒)
0	=	Not at all	2	=	Somewhat		
1	=	A little bit	3	=	Quite a bit		
		4	=	Very much			
19.	I feel nervous.	0	1	2	3	4	
20.	I worry about the impact my loved one's illness has had on my children or other family members.	0	1	2	3	4	
21.	I have difficulty dealing with my loved one's changing eating habits.	0	1	2	3	4	
22.	I have developed a closer relationship with my loved one.	0	1	2	3	4	
23.	I feel adequately informed about my loved one's illness.	0	1	2	3	4	
24.	It bothers me that I need to be available to chauffeur my loved one to appointments.	0	1	2	3	4	
25.	I fear the adverse effects of treatment on my loved one.	0	1	2	3	4	
26.	The responsibility I have for my loved one's care at home is overwhelming.	0	1	2	3	4	
27.	I am glad that my focus is on getting my loved one well.	0	1	2	3	4	
28.	Family communication has increased.	0	1	2	3	4	
29.	It bothers me that my priorities have changed.	0	1	2	3	4	
30.	The need to protect my loved one bothers me.	0	1	2	3	4	
31.	It upsets me to see my loved one deteriorate.	0	1	2	3	4	
32.	The need to manage my loved one's pain is overwhelming.	0	1	2	3	4	
33.	I am discouraged about the future.	0	1	2	3	4	
34.	I am satisfied with the support I get from my family.	0	1	2	3	4	
35.	It bothers me that other family members have not shown interest in taking care of my loved one.	0	1	2	3	4	

EPIC-26
The Expanded Prostate Cancer Index Composite
Short Form

This questionnaire is designed to measure Quality of Life issues in patients with Prostate cancer. To help us get the most accurate measurement, it is important that you answer all questions honestly and completely.

Remember, as with all medical records, information contained within this survey will remain strictly confidential.

Today's Date (please enter date when survey completed): Month_____Day_____Year_____

Name (optional): _____

Date of Birth (optional): Month_____Day_____Year_____

1. Over the **past 4 weeks**, how often have you leaked urine?

- More than once a day..... 1
 About once a day..... 2
 More than once a week..... 3 (Circle one number)
 About once a week..... 4
 Rarely or never..... 5

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2. Which of the following best describes your urinary control **during the last 4 weeks**?

- No urinary control whatsoever..... 1
 Frequent dribbling..... 2 (Circle one number)
 Occasional dribbling..... 3
 Total control..... 4

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3. How many pads or adult diapers per day did you usually use to control leakage **during the last 4 weeks**?

- None 0
 1 pad per day..... 1
 2 pads per day..... 2 (Circle one number)
 3 or more pads per day..... 3

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4. How big a problem, if any, has each of the following been for you **during the last 4 weeks**?

(Circle one number on each line)

	No <u>Problem</u>	Very Small <u>Problem</u>	Small <u>Problem</u>	Moderate <u>Problem</u>	Big <u>Problem</u>
a. Dripping or leaking urine	0	1	2	3	4
b. Pain or burning on urination.....	0	1	2	3	4
c. Bleeding with urination.....	0	1	2	3	4
d. Weak urine stream or incomplete emptying	0	1	2	3	4
e. Need to urinate frequently during the day	0	1	2	3	4

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29/

30/

31/

33/

5. Overall, how big a problem has your urinary function been for you **during the last 4 weeks**?

- No problem..... 1
 Very small problem..... 2
 Small problem..... 3 (Circle one number)
 Moderate problem..... 4
 Big problem..... 5

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6. How big a problem, if any, has each of the following been for you? (Circle one number on each line)

	<u>No Problem</u>	<u>Very Small Problem</u>	<u>Small Problem</u>	<u>Moderate Problem</u>	<u>Big Problem</u>	
a. Urgency to have a bowel movement	0	1	2	3	4	49/
b. Increased frequency of bowel movements.....	0	1	2	3	4	50/
c. Losing control of your stools.....	0	1	2	3	4	52/
d. Bloody stools	0	1	2	3	4	53/
e. Abdominal/ Pelvic/Rectal pain...	0	1	2	3	4	54/

7. Overall, how big a problem have your bowel habits been for you **during the last 4 weeks?**

No problem.....	1					
Very small problem.....	2					
Small problem.....	3					(Circle one number)
Moderate problem.....	4					
Big problem.....	5					

8. How would you rate each of the following **during the last 4 weeks?** (Circle one number on each line)

	<u>Very Poor to None</u>	<u>Poor</u>	<u>Fair</u>	<u>Good</u>	<u>Very Good</u>	
a. Your ability to have an erection?.....	1	2	3	4	5	57/
b. Your ability to reach orgasm (climax)?.....	1	2	3	4	5	58/

9. How would you describe the usual **QUALITY** of your erections **during the last 4 weeks?**

None at all.....	1					
Not firm enough for any sexual activity.....	2					
Firm enough for masturbation and foreplay only.....	3					(Circle one number)
Firm enough for intercourse.....	4					

10. How would you describe the **FREQUENCY** of your erections **during the last 4 weeks?**

I NEVER had an erection when I wanted one.....	1					
I had an erection LESS THAN HALF the time I wanted one.....	2					
I had an erection ABOUT HALF the time I wanted one	3					(Circle one number)
I had an erection MORE THAN HALF the time I wanted one.....	4					
I had an erection WHENEVER I wanted one.....	5					

11. Overall, how would you rate your ability to function sexually **during the last 4 weeks?**

- Very poor..... 1
 Poor..... 2
 Fair..... 3 (Circle one number)
 Good..... 4
 Very good..... 5

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12. Overall, how big a problem has your sexual function or lack of sexual function been for you **during the last 4 weeks?**

- No problem..... 1
 Very small problem..... 2
 Small problem..... 3 (Circle one number)
 Moderate problem..... 4
 Big problem..... 5

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13. How big a problem **during the last 4 weeks**, if any, has each of the following been for you?

(Circle one number on each line)

	<u>No Problem</u>	<u>Very Small Problem</u>	<u>Small Problem</u>	<u>Moderate Problem</u>	<u>Big Problem</u>	
a. Hot flashes.....	0	1	2	3	4	74/
b. Breast tenderness/enlargement..	0	1	2	3	4	75/
c. Feeling depressed.....	0	1	2	3	4	77/
d. Lack of energy.....	0	1	2	3	4	78/
e. Change in body weight.....	0	1	2	3	4	79/

THANK YOU VERY MUCH!!

Expanded Prostate Cancer Index Composite for Clinical Practice (EPIC-CP)

Prostate Cancer Quality of Life (QOL)

Patient Name: _____ Date of Birth: _____

Physician: _____ Date of Visit: _____

Patients: Please answer the following questions by circling the appropriate answer. All questions are about your health and symptoms in the **LAST FOUR WEEKS**.

Select ONE answer for each question:

1. Overall, how much of a problem has your urinary function been for you?				
No Problem	Very small problem	Small problem	Moderate problem	Big problem

2. Which of the following best describes your urinary control?				
0-Total control	1-Occasional dribbling	2-Frequent dribbling	4- No urinary control	

3. How many pads or adult diapers per day have you been using for urinary leakage?				
0-None	1-One pad per Day	2-Two pads per Day	4- Three or more pads	

4. How big a problem, if any has urinary dripping or leakage been for you?				
0-No problem	1-Very small problem	2-Small problem	3-Moderate problem	4-Big problem
CLINICIANS: Add the answers from questions 2-4 to calculate the Urinary Incontinence Symptom Score (out of 12)				

5. How big a problem, if any, has each of the following been for you?						
	No problem	Very small problem	Small problem	Moderate problem	Big problem	
a. Pain or burning with urination	0	1	2	3	4	
b. Weak urine stream/incomplete bladder emptying	0	1	2	3	4	
c. Need to urinate frequently	0	1	2	3	4	
CLINICIANS: ADD the answers from questions 5a-5c to calculate the Urinary Irritation/Obstructive Symptom Score (out of 12)						

6. How big a problem, if any, has each of the following been for you?						
	No problem	Very small problem	Small problem	Moderate problem	Big problem	
a. Rectal pain or urgency of bowel movements	0	1	2	3	4	
b. Increased frequency of your bowel movements	0	1	2	3	4	
c. Overall problems with your bowel movements	0	1	2	3	4	
CLINICIANS: ADD the answers from questions 6a-6c to calculate the Bowel Symptom Score (out of 12)						

7. How do you rate your ability to reach orgasm (climax)?				
0- Very good	1-Good	2-Fair	3-Poor	4-Very poor to none

8. How would you describe the usual quality of your erections?				
0- Firm enough for intercourse	1-firm enough for masturbation and foreplay	2-Not firm enough for any sexual activity	4-None at all	

9. Overall, how much of a problem has your sexual function or lack of sexual function been for you?				
0-No problem	1-Very small problem	2-Small problem	3-Moderate problem	4-Big problem

10. How big a problem, if any, has each of the following been for you?						
	No problem	Very small problem	Small problem	Moderate problem	Big problem	
a. Hot flashes or breast tenderness/enlargement	0	1	2	3	4	
b. Feeling depressed	0	1	2	3	4	
c. Lack of energy	0	1	2	3	4	
CLINICIANS: ADD the answers from question s10a-10c to calculate the Vitality/Hormonal Symptom Score (out of 12)						

CLINICIANS: ADD the five domain summary scores to calculate the Overall Prostate Cancer QOL Score (out of 60)					
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41670

OMB #: 0935-0118
Exp. Date: 1/31/2013

MEPS

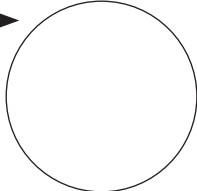
Medical Expenditure Panel Survey

Your Experiences with Cancer

- ➔ This survey is about the lasting effects of cancer and cancer treatments on the lives of those who have been diagnosed with cancer.
- ➔ The survey will ask about the effects of cancer, its treatment, or the lasting effects of that treatment on your employment, finances, health insurance coverage, and life in general. The goal of this survey is to help improve experiences of people diagnosed with cancer in the future. Please take the time to answer these questions about your experiences with cancer.
- ➔ Your participation is voluntary and all of your answers will be kept confidential to the extent permitted by law. If you have any questions about this survey, please call Alex Scott at 1-800-945-MEPS (6377).
- ➔ The person named in the box below should complete this survey:

NAME: _____												

DOB: <table><tr><td></td><td></td></tr></table> / <table><tr><td></td><td></td></tr></table> / <table><tr><td></td><td></td><td></td><td></td></tr></table>									PID: <table><tr><td></td><td></td><td></td></tr></table>			
	MONTH	DAY	YEAR									
RUID: <table><tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>												

- ➔ When you have completed this survey, fold it, then seal with this label →  and place it in the envelope provided.
- ➔ Complete your survey now, by continuing to the next page.

Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). That law requires that information collected for research conducted or supported by AHRQ that identifies individuals or establishments be used only for the purpose for which it was supplied unless you consent to the use of the information for another purpose. Public reporting burden for this collection of information is estimated to average 20 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-0118), AHRQ, 540 Gaither Road, Room #5036, Rockville, MD 20850.



The Agency for Healthcare Research and Quality and
The Centers for Disease Control and Prevention of the
U.S. Department of Health and Human Services

Attach label here (see back→cover) →

Section 1. Cancer History

- ▶ This first section asks about your cancer history.
- ▶ Answer each question by marking ☒ your response or filling in a number when necessary.

1. Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind?

- ☐ Yes
☐ No

Please stop. Thank you for your time. This survey is complete.

2. Was your only cancer diagnosis or treatment before the age of 18?

- ☐ Yes
☐ No

Please stop. Thank you for your time. This survey is complete.

3. Are you currently being treated for cancer – that is are you planning or recovering from cancer surgery, or receiving chemotherapy, radiation therapy, or hormonal therapy for your cancer?

- ☐ Yes → **GO TO Question 8**
☐ No

4. To the best of your knowledge, are you now free of cancer?

- ☐ Yes
☐ No
☐ I don't know

5. About how long ago did you receive your last cancer treatment?

- ☐ Less than 1 year ago
☐ 1 year ago to less than 3 years ago
☐ 3 years ago to less than 5 years ago
☐ 5 years ago to less than 10 years ago
☐ 10 years ago to 20 years ago
☐ More than 20 years ago
☐ I have not been treated for cancer

6. Did a doctor or other health professional ever tell you that your cancer had come back?

- ☐ Yes
☐ No → **GO TO Section 2, page 2**

7. What was the most recent year a doctor or health professional told you that your cancer had come back?

→ **GO TO Section 2, page 2**
 YEAR

8. Is this the first time you have been treated for any type of cancer?

- ☐ Yes
☐ No

▶ **Continue with Section 2, page 2.**

Section 2. Changes to Your Work Schedule

9. At any time from when you were first diagnosed with cancer until now, were you working for pay at a job or business?

☐

Yes

☐

No → **GO TO Question 47, page 6**

- ▶ These next questions ask about different ways cancer, its treatment, or the lasting effects of that treatment may have affected your work – that is, your hours, duties, or employment status.
- ▶ As you answer these questions, please think about the entire time from when you were first diagnosed with cancer to now.
- ▶ If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

10. At any time since your first cancer diagnosis, did you take extended paid time off from work, unpaid time off, or make a change in your hours, duties or employment status?

☐

Yes → **GO TO Question 13**

☐

No

11. At any time since your first cancer diagnosis, did you ask for extended paid time off from work, unpaid time off, or a change in your hours, duties or employment status?

☐

Yes

☐

No → **GO TO Question 36, page 4**

12. Did you ask for these work changes...

☐

Because of your cancer, its treatment or its lasting effects?

☐

Some other reason?

GO TO Question 36, page 4

13. Did you make these work changes...

☐

Because of your cancer, its treatment or its lasting effects?

☐

Some other reason?

→ **GO TO Question 36, page 4**

14. Did you ever take extended paid time off from work (vacation, sick time and/or disability leave)? By extended time off, we mean more than an occasional day off here and there.

☐

Yes

☐

No → **GO TO Question 18, page 3**

15. When did you take extended paid time off from work?

Mark ☒ all that apply.

☐

At the time of diagnosis

☐

During treatment

☐

Less than one year after treatment was finished

☐

One year or more after treatment was finished

16. What do you estimate was the total amount of extended paid time off from work that you took?

☐

Less than 2 months

☐

2 months to less than 6 months

☐

6 months to less than 1 year

☐

1 year to 3 years

☐

More than 3 years

17. Is your extended paid time off from work ongoing?

- ☐ Yes
☐ No

18. Did you ever take unpaid time off from work?

- ☐ Yes
☐ No → **GO TO Question 22**

19. When did you take unpaid time off from work?

Mark ☒ all that apply.

- ☐ At the time of diagnosis
☐ During treatment
☐ Less than one year after treatment was finished
☐ One year or more after treatment was finished

20. What do you estimate was the total amount of unpaid time off from work that you took?

- ☐ Less than 2 months
☐ 2 months to less than 6 months
☐ 6 months to less than 1 year
☐ 1 year to 3 years
☐ More than 3 years

21. Is your unpaid time off ongoing?

- ☐ Yes
☐ No

22. Did you ever change from working part-time to working full-time?

- ☐ Yes
☐ No → **GO TO Question 26**

23. When did you change from working part-time to working full-time?

Mark ☒ all that apply.

- ☐ At the time of diagnosis
☐ During treatment
☐ Less than one year after treatment was finished
☐ One year or more after treatment was finished

24. What do you estimate was the total amount of time you worked full-time?

- ☐ Less than 2 months
☐ 2 months to less than 6 months
☐ 6 months to less than 1 year
☐ 1 year to 3 years
☐ More than 3 years

25. Is this change ongoing?

- ☐ Yes
☐ No

26. Did you ever change from working full-time to working part-time?

- ☐ Yes
☐ No → **GO TO Question 30, page 4**

27. When did you change from working full-time to working part-time?

Mark ☒ all that apply.

- ☐ At the time of diagnosis
☐ During treatment
☐ Less than one year after treatment was finished
☐ One year or more after treatment was finished

28. What do you estimate was the total amount of time you worked part-time?

- ☐ Less than 2 months
- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years

29. Is this change ongoing?

- ☐ Yes
- ☐ No

30. Did you ever change from a set work schedule, where you start and end at the same time every day, to a flexible work schedule, where your start and end times vary from day-to-day?

- ☐ Yes
- ☐ No → **GO TO Question 32**

31. When did you change to a flexible work schedule?

Mark ☒ all that apply.

- ☐ At the time of diagnosis
- ☐ During treatment
- ☐ Less than one year after treatment was finished
- ☐ One year or more after treatment was finished

32. Did you ever change to a less demanding job?

- ☐ Yes
- ☐ No → **GO TO Question 36**

33. When did you change to a less demanding job?

Mark ☒ all that apply.

- ☐ At the time of diagnosis
- ☐ During treatment
- ☐ Less than one year after treatment was finished
- ☐ One year or more after treatment was finished

34. How long did you stay in the less demanding job?

- ☐ Less than 2 months
- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years

35. Is this change ongoing?

- ☐ Yes
- ☐ No

36. Did you make any other type of work arrangements because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes
- ☐ No → **GO TO Question 37, page 5**

→ **Please describe:**

37. Because of your cancer, its treatment, or the lasting effects of that treatment, did you ever decide not to pursue an advancement or promotion?

- ☐ Yes
☐ No

38. Because of your cancer, its treatment, or the lasting effects of that treatment, did you retire earlier than you had planned?

- ☐ Yes → **GO TO Section 3**
☐ No

39. Because of your cancer, its treatment, or the lasting effects of that treatment, did you delay retirement beyond when you had planned?

- ☐ Yes
☐ No

Section 3. Other Aspects of Work

► Please continue to think about all your work experiences from the time you were first diagnosed with cancer to now.

► If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

40. Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any physical tasks required by your job?

- ☐ Yes
☐ No
☐ I was never required to perform physical tasks as part of my job

41. Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any mental tasks required by your job?

- ☐ Yes
☐ No

42. Did you ever feel that, because of your cancer, its treatment, or the lasting effects of that treatment, you were less productive at work?

- ☐ Yes
☐ No

43. Did you ever worry that, because of the effects of cancer on your health, you might be forced to retire or quit work before you are ready?

- ☐ Yes
☐ No

44. Did you ever stay at a job in part because you were concerned about losing your health insurance?

- ☐ Yes
☐ No → **GO TO Question 46**

45. Were you concerned about losing your health insurance because of your cancer?

- ☐ Yes
☐ No

46. Thinking about your work life or career, what effect has your experience with cancer, its treatment, or the lasting effects of that treatment had on it?

- ☐ Mostly positive effect
☐ Mostly negative effect
☐ Equally positive and negative effect
☐ Neither positive nor negative effect

47. Did your spouse or significant other ever stay at a job in part because he/she was concerned about losing health insurance for the family?

- ☐ Yes
☐ No
☐ Does not apply

Section 4. Caregivers

- ▶ This section is about caregivers, meaning friends or family members who may have provided help with getting to the doctor, going to appointments with you, making decisions about treatment, or providing other types of care and support during or after cancer treatment.
- ▶ Please continue to think about the time you were first diagnosed with cancer to now.
- ▶ If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

48. Since the time you were first diagnosed with cancer, has any friend or family member provided care to you during or after your cancer treatment?

- ☐ Yes
☐ No → **GO TO Section 5, page 8**

49. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers ever take extended paid time off from work, unpaid time off, or make a change in their hours, duties or employment status?

- ☐ Yes
☐ No → **GO TO Question 63, page 8**
☐ None of my caregivers were employed while caring for me
 → **GO TO Section 5, page 8**
☐ I don't know
 → **GO TO Question 63, page 8**

GO TO Question 50, page 7

50. Did any of your caregivers ever take extended paid time off from work, unpaid time off, or make a change in their hours, duties, or employment status for at least 2 months?

- ☐ Yes
☐ No → *GO TO Question 63, page 8*

51. Did any of your caregivers take extended paid time off from work (vacation and/or sick time)?

- ☐ Yes
☐ No → *GO TO Question 54*

52. How long do you estimate this caregiver took extended paid time off from work?

- ☐ 2 months to less than 6 months
☐ 6 months to less than 1 year
☐ 1 year to 3 years
☐ More than 3 years

53. Is this caregiver's extended paid time off from work ongoing?

- ☐ Yes
☐ No

54. Did any of your caregivers take unpaid time off from work?

- ☐ Yes
☐ No → *GO TO Question 57*

55. How long do you estimate this caregiver took unpaid time off from work?

- ☐ 2 months to less than 6 months
☐ 6 months to less than 1 year
☐ 1 year to 3 years
☐ More than 3 years

56. Is this caregiver's unpaid time off ongoing?

- ☐ Yes
☐ No

57. Did any of your caregivers change from working part-time to working full-time?

- ☐ Yes
☐ No → *GO TO Question 60*

58. How long do you estimate this caregiver worked full-time?

- ☐ 2 months to less than 6 months
☐ 6 months to less than 1 year
☐ 1 year to 3 years
☐ More than 3 years

59. Is this change ongoing?

- ☐ Yes
☐ No

60. Did any of your caregivers change from working full-time to working part-time?

- ☐ Yes
☐ No → *GO TO Question 63, page 8*

61. How long do you estimate this caregiver worked part-time?

- ☐ 2 months to less than 6 months
☐ 6 months to less than 1 year
☐ 1 year to 3 years
☐ More than 3 years

62. Is this change ongoing?

- ☐ Yes
☐ No

63. Did any of your caregivers make any other type of work arrangements because of your cancer, its treatment, or the lasting effects of that treatment?

☐ Yes

☐ No

☐ I don't know

} **GO TO Question 64**

→ **Please describe:**

64. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers change to a less demanding job?

☐ Yes

☐ No

☐ I don't know

65. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers retire early?

☐ Yes

☐ No

☐ I don't know

66. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers delay retirement?

☐ Yes

☐ No

☐ I don't know

Section 5. Experiences with Health Insurance

- ▶ The next few questions are about health insurance coverage from the time you were first diagnosed with cancer to now.
- ▶ If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

67. At any time from when you were first diagnosed with cancer to now, were you covered by health insurance that paid for all or part of your medical care, tests or cancer treatment?

☐ Yes

☐ No

☐ I don't know

} **GO TO Question 70**

68. Was there ever a time when health insurance refused to cover a visit for your cancer to the doctor or facility of your choice?

☐ Yes

☐ No

☐ Does not apply

69. Was there ever a time when health insurance refused to cover a second opinion about your cancer?

☐ Yes

☐ No

☐ I never asked for a second opinion

70. Were you ever denied health insurance coverage because of your cancer?

☐ Yes

☐ No

☐ I never applied for health insurance

Section 6. The Effects of Cancer and Its Treatment on Finances

- ▶ The next questions ask about different kinds of financial burden you or your family may have experienced because of your cancer, its treatment, or the lasting effects of that treatment.
- ▶ Please continue to think about all the time from when you were first diagnosed with cancer to now.
- ▶ If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

71. Have you or has anyone in your family had to borrow money or go into debt because of your cancer, its treatment, or the lasting effects of that treatment?

☐ Yes

☐ No → **GO TO Question 74**

72. How much did you or your family borrow, or how much debt did you incur because of your cancer, its treatment, or the lasting effects of that treatment?

☐ Less than \$10,000

☐ \$10,000 to \$24,999

☐ \$25,000 to \$49,999

☐ \$50,000 to \$74,999

☐ \$75,000 to \$99,999

☐ \$100,000 or more

73. Did you or your family ever file for bankruptcy because of your cancer, its treatment, or the lasting effects of that treatment?

☐ Yes

☐ No

74. Have you or your family had to make any other kinds of financial sacrifices because of your cancer, its treatment, or the lasting effects of that treatment?

☐ Yes

☐ No → **GO TO Question 75**

▶ **Please describe:**

75. Have you ever worried about having to pay large medical bills related to your cancer?

☐ Yes

☐ No

76. Please think about medical care visits for cancer, its treatment, or the lasting effects of that treatment. Have you ever been unable to cover your share of the cost of those visits?

☐ Yes

☐ No

▶ **Continue with Section 7, page 10.**

Section 7. Medical Care for Cancer

- ▶ These next questions ask about certain experiences you may have had when receiving medical care for cancer from the time you were first diagnosed to now.
- ▶ If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

77. At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you...

a. The need for regular follow-up care and monitoring even after completing your treatment?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

b. Late or long-term side effects of cancer treatment you may experience over time?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

c. Your emotional or social needs related to your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

d. Lifestyle or health recommendations such as diet, exercise, quitting smoking?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

78. At any time since you were first diagnosed with cancer, did you get all of the medical care, tests, or treatments that you or your doctor believed were necessary?

☐ Yes → **GO TO Section 8, page 11**

☐ No

79. Which of these are reasons you did not get all of the medical care, tests, or treatments you or a doctor believed you needed?

Mark ☒ yes or no for each item below.

- | | Yes,
a reason | No, not
a reason |
|--|--------------------------|--------------------------|
| a. Couldn't afford care | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Insurance company wouldn't approve or pay for care | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Doctor did not accept your insurance | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Had problems getting to doctor's office | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Couldn't get time off from work | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Didn't know where to go to get care | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Couldn't get child care/adult care | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Didn't have time, care/ test/treatment took too long | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Other reason | <input type="checkbox"/> | <input type="checkbox"/> |

! If you answered 'Yes' to only one reason in Question 79, GO TO Section 8 on page 11. Otherwise continue with Question 80, on page 11.

80. Which one of these is the main reason that you did not get all of the medical care, tests, or treatments you or a doctor believed you needed?

Mark ☒ ONE only.

- ☐ Couldn't afford care
- ☐ Insurance company wouldn't approve or pay for care
- ☐ Doctor didn't accept your insurance
- ☐ Had problems getting to the doctors' office
- ☐ Couldn't get time off from work
- ☐ Didn't know where to go to get care
- ☐ Couldn't get child care/adult care
- ☐ Didn't have time, care/test/treatment took too long

☐ Some other reason.

Please describe:

Section 8. The Effects of Cancer and Its Treatment on Life in General

- ▶ The last few questions in the survey ask about how your cancer, its treatment and the lasting effects of that treatment may have influenced certain parts of your life.
- ▶ If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

81. Did your cancer, its treatment, or the lasting effects of that treatment ever limit the kind or amount of activities you do outside of work, such as shopping, child care, exercising, studying, work around the house, and so on?

- ☐ Yes
- ☐ No → **GO TO Question 84**

82. How long were you or have you been limited in the kind or amount of usual daily activities?

- ☐ Less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to less than 3 years
- ☐ 3 years to less than 5 years
- ☐ 5 years to less than 10 years
- ☐ More than 10 years

83. Is this limitation ongoing?

- ☐ Yes
- ☐ No

84. Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any mental tasks as part of your usual daily activities?

- ☐ Yes
- ☐ No

85. Have you ever asked for help getting to a doctor or other healthcare provider because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes
☐ No → **GO TO Question 87**

86. Did you ever receive help getting to a doctor or other healthcare provider?

- ☐ Yes
☐ No

87. Have you ever asked for help understanding health insurance or medical bills related to your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes
☐ No → **GO TO Question 89**

88. Did you ever receive help understanding health insurance or medical bills?

- ☐ Yes
☐ No

89. How often do you worry that your cancer may come back or get worse?

- ☐ Never → **GO TO Question 91**
☐ Rarely
☐ Sometimes
☐ Often
☐ All the time

90. How often do you worry that if your cancer came back or got worse it might keep you from fulfilling responsibilities at home or at work?

- ☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ All the time

91. In your own opinion, what do you think are the chances that your cancer will come back or get worse within the next 10 years?

- ☐ Very low
☐ Fairly low
☐ Moderate
☐ Fairly high
☐ Very high
☐ I don't know

92. Have any of the following been positive things about your experiences with your cancer, its treatment, or the lasting effects of that treatment?

Mark ☒ yes or no for each item below.

	Yes	No
a. It has made me a stronger person	<input type="checkbox"/>	<input type="checkbox"/>
b. I can cope better with life's challenges	<input type="checkbox"/>	<input type="checkbox"/>
c. It became a reason to make positive changes in my life	<input type="checkbox"/>	<input type="checkbox"/>
d. It has made me have healthier habits	<input type="checkbox"/>	<input type="checkbox"/>

93. Please use the space below to tell us anything else about your experiences with cancer.

- ▶ Thank you for completing this survey. Please place this survey in the envelope provided to you and give it to the MEPS interviewing team member.
- ▶ If the interviewer is no longer available, place the survey in the return envelope provided to you by the interviewer. If the envelope is missing, mail this survey to:

MEPS
c/o Westat
1600 Research Blvd, Room GA51
Rockville, MD 20850



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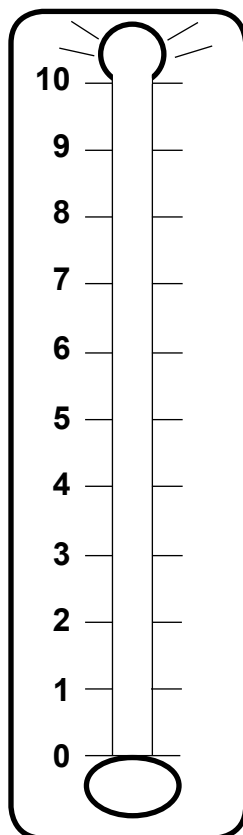


NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress



No distress

PROBLEM LIST

Please indicate if any of the following has been a problem for you in the past week including today.

Be sure to check YES or NO for each.

YES NO Practical Problems

- | | | |
|--------------------------|--------------------------|---------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Child care |
| <input type="checkbox"/> | <input type="checkbox"/> | Housing |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance/financial |
| <input type="checkbox"/> | <input type="checkbox"/> | Transportation |
| <input type="checkbox"/> | <input type="checkbox"/> | Work/school |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment decisions |

Family Problems

- | | | |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with children |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with partner |
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children |
| <input type="checkbox"/> | <input type="checkbox"/> | Family health issues |

Emotional Problems

- | | | |
|--------------------------|--------------------------|--------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Depression |
| <input type="checkbox"/> | <input type="checkbox"/> | Fears |
| <input type="checkbox"/> | <input type="checkbox"/> | Nervousness |
| <input type="checkbox"/> | <input type="checkbox"/> | Sadness |
| <input type="checkbox"/> | <input type="checkbox"/> | Worry |
| <input type="checkbox"/> | <input type="checkbox"/> | Loss of interest in usual activities |

- | | | |
|--------------------------|--------------------------|-------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Spiritual/religious concerns</u> |
|--------------------------|--------------------------|-------------------------------------|

Other Problems: _____

YES NO Physical Problems

- | | | |
|--------------------------|--------------------------|------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Appearance |
| <input type="checkbox"/> | <input type="checkbox"/> | Bathing/dressing |
| <input type="checkbox"/> | <input type="checkbox"/> | Breathing |
| <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination |
| <input type="checkbox"/> | <input type="checkbox"/> | Constipation |
| <input type="checkbox"/> | <input type="checkbox"/> | Diarrhea |
| <input type="checkbox"/> | <input type="checkbox"/> | Eating |
| <input type="checkbox"/> | <input type="checkbox"/> | Fatigue |
| <input type="checkbox"/> | <input type="checkbox"/> | Feeling swollen |
| <input type="checkbox"/> | <input type="checkbox"/> | Fevers |
| <input type="checkbox"/> | <input type="checkbox"/> | Getting around |
| <input type="checkbox"/> | <input type="checkbox"/> | Indigestion |
| <input type="checkbox"/> | <input type="checkbox"/> | Memory/concentration |
| <input type="checkbox"/> | <input type="checkbox"/> | Mouth sores |
| <input type="checkbox"/> | <input type="checkbox"/> | Nausea |
| <input type="checkbox"/> | <input type="checkbox"/> | Nose dry/congested |
| <input type="checkbox"/> | <input type="checkbox"/> | Pain |
| <input type="checkbox"/> | <input type="checkbox"/> | Sexual |
| <input type="checkbox"/> | <input type="checkbox"/> | Skin dry/itchy |
| <input type="checkbox"/> | <input type="checkbox"/> | Sleep |
| <input type="checkbox"/> | <input type="checkbox"/> | Substance abuse |
| <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet |

The Patient Health Questionnaire-2 (PHQ-2) - Overview

The PHQ-2 inquires about the frequency of depressed mood and anhedonia over the past two weeks. The PHQ-2 includes the first two items of the PHQ-9.

- The purpose of the PHQ-2 is not to establish final a diagnosis or to monitor depression severity, but rather to screen for depression in a “first step” approach.
- Patients who screen positive should be further evaluated with the PHQ-9 to determine whether they meet criteria for a depressive disorder.

Clinical Utility

Reducing depression evaluation to two screening questions enhances routine inquiry about the most prevalent and treatable mental disorder in primary care.

Scoring

A PHQ-2 score ranges from 0-6. The authors¹ identified a PHQ-2 cutoff score of 3 as the optimal cut point for screening purposes and stated that a cut point of 2 would enhance sensitivity, whereas a cut point of 4 would improve specificity.

Psychometric Properties¹

Major Depressive Disorder (7% prevalence)				Any Depressive Disorder (18% prevalence)			
PHQ-2 Score	Sensitivity	Specificity	Positive Predictive Value (PPV*)	PHQ-2 Score	Sensitivity	Specificity	Positive Predictive Value (PPV*)
1	97.6	59.2	15.4	1	90.6	65.4	36.9
2	92.7	73.7	21.1	2	82.1	80.4	48.3
3	82.9	90.0	38.4	3	62.3	95.4	75.0
4	73.2	93.3	45.5	4	50.9	97.9	81.2
5	53.7	96.8	56.4	5	31.1	98.7	84.6
6	26.8	99.4	78.6	6	12.3	99.8	92.9

* Because the PPV varies with the prevalence of depression, the PPV will be higher in settings with a higher prevalence of depression and lower in settings with a lower prevalence.

1. Kroenke K, Spitzer RL, Williams JB. The Patient Health Questionnaire-2: Validity of a Two-Item Depression Screener. *Medical Care* 2003, (41) 1284-1294.

The Patient Health Questionnaire-2 (PHQ-2)

Patient Name _____ Date of Visit _____

Over the past 2 weeks, how often have you been bothered by any of the following problems?	Not At all	Several Days	More Than Half the Days	Nearly Every Day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed or hopeless	0	1	2	3

The Patient Health Questionnaire (PHQ-9) - Overview

The PHQ-9 is a multipurpose instrument for screening, diagnosing, monitoring and measuring the severity of depression:

- The PHQ-9 incorporates DSM-IV depression diagnostic criteria with other leading major depressive symptoms into a brief self-report tool.
- The tool rates the frequency of the symptoms which factors into the scoring severity index.
- Question 9 on the PHQ-9 screens for the presence and duration of suicide ideation.
- A follow up, non-scored question on the PHQ-9 screens and assigns weight to the degree to which depressive problems have affected the patient's level of function.

Clinical Utility

The PHQ-9 is brief and useful in clinical practice. The PHQ-9 is completed by the patient in minutes and is rapidly scored by the clinician. The PHQ-9 can also be administered repeatedly, which can reflect improvement or worsening of depression in response to treatment.

Scoring

See PHQ-9 Scoring on next page.

Psychometric Properties

- The diagnostic validity of the PHQ-9 was established in studies involving 8 primary care and 7 obstetrical clinics.
- PHQ scores ≥ 10 had a sensitivity of 88% and a specificity of 88% for major depression.
- PHQ-9 scores of 5, 10, 15, and 20 represents mild, moderate, moderately severe and severe depression.¹

1. Kroenke K, Spitzer R, Williams W. The PHQ-9: Validity of a brief depression severity measure. *JGIM*, 2001, 16:606-616

The Patient Health Questionnaire (PHQ-9) Scoring

Use of the PHQ-9 to Make a Tentative Depression Diagnosis:

The clinician should rule out physical causes of depression, normal bereavement and a history of a manic/hypomanic episode

Step 1: Questions 1 and 2

Need one or both of the first two questions endorsed as a "2" or a "3"
(2 = "More than half the days" or 3 = "Nearly every day")

Step 2: Questions 1 through 9

Need a total of five or more boxes endorsed within the shaded area of the form to arrive at the total symptom count. (Questions 1-8 must be endorsed as a "2" or a "3"; Question 9 must be endorsed as "1" a "2" or a "3")

Step 3: Question 10

This question must be endorsed as "Somewhat difficult" or "Very difficult" or "Extremely difficult"

Use of the PHQ-9 for Treatment Selection and Monitoring

Step 1

A depression diagnosis that warrants treatment or a treatment change, needs at least one of the first two questions endorsed as positive ("more than half the days" or "nearly every day") in the past two weeks. In addition, the tenth question, about difficulty at work or home or getting along with others should be answered at least "somewhat difficult"

Step 2

Add the total points for each of the columns 2-4 separately
(Column 1 = Several days; Column 2 = More than half the days; Column 3 = Nearly every day. Add the totals for each of the three columns together. This is the Total Score
The Total Score = the Severity Score

Step 3

Review the Severity Score using the following TABLE.

PHQ-9 Score	Provisional Diagnosis	Treatment Recommendation <i>Patient Preferences should be considered</i>
5-9	Minimal Symptoms*	Support, educate to call if worse, return in one month
10-14	Minor depression ++ Dysthymia* Major Depression, mild	Support, watchful waiting Antidepressant or psychotherapy Antidepressant or psychotherapy
15-19	Major depression, moderately severe	Antidepressant or psychotherapy
>20	Major Depression, severe	Antidepressant and psychotherapy (especially if not improved on monotherapy)

* If symptoms present \geq two years, then probable chronic depression which warrants antidepressants or psychotherapy (ask "In the past 2 years have you felt depressed or sad most days, even if you felt okay sometimes?")

++ If symptoms present \geq one month or severe functional impairment, consider active treatment

The Patient Health Questionnaire (PHQ-9)

Patient Name _____ Date of Visit _____

Over the past 2 weeks, how often have you been bothered by any of the following problems?

	Not At all	Several Days	More Than Half the Days	Nearly Every Day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed or hopeless	0	1	2	3
3. Trouble falling asleep, staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself - or that you're a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or, the opposite - being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

Column Totals _____ + _____ + _____

Add Totals Together _____

10. If you checked off any problems, how difficult have those problems made it for you to
Do your work, take care of things at home, or get along with other people?

☐ Not difficult at all ☐ Somewhat difficult ☐ Very difficult ☐ Extremely difficult

The Memorial Anxiety Scale for Prostate Cancer

Validation of a New Scale to Measure Anxiety in Men with Prostate Cancer

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BACKGROUND. The psychological difficulties facing men with prostate cancer are acknowledged widely, yet identifying men who may benefit from mental health treatment has proven to be a challenging task. The authors developed the Memorial Anxiety Scale for Prostate Cancer (MAX-PC) to facilitate the identification and assessment of men with prostate cancer-related anxiety. This scale consists of three subscales that measure general prostate cancer anxiety, anxiety related to prostate specific antigen (PSA) levels in particular, and fear of recurrence.

METHODS. Ambulatory men with prostate cancer ($n = 385$ patients) were recruited from clinics throughout the United States. Prior to routine PSA tests, participants completed a *baseline* assessment packet that included the Hospital Anxiety and Depression Scale; the Distress Thermometer; the Functional Assessment of Cancer Therapy Scale, Prostate Module; and measures of role functioning, sleep, and urinary functioning. PSA values from the last three tests also were collected. Follow-up evaluation was completed within 2 weeks after patients learned of their PSA test result using a subset of these scales.

RESULTS. Analysis of the MAX-PC revealed a high degree of internal consistency and test-retest reliability for the total score and for the three subscales, although reliability was somewhat weaker for the PSA Anxiety Scale. Concurrent validity was demonstrated by correlations between the MAX-PC and measures of anxiety. Overall changes in PSA levels were correlated only modestly with changes in MAX-PC scores (correlation coefficient, 0.13; $P = 0.02$).

CONCLUSIONS. The MAX-PC appears to be a valid and reliable measure of anxiety in men with prostate cancer receiving ambulatory care. *Cancer* 2003;97:2910-8.

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KEYWORDS: anxiety, cancer, prostate, scale development.

The prostate is the most common site of cancer in older males in the U.S. An estimated 198,100 new cases of prostate cancer are diagnosed annually, 80% of which occur in men older than 65 years.¹ Not only does a diagnosis of prostate cancer entail uncertainties regarding the possibility of functional disabilities or even death, but these older men also are experiencing the losses related to the later phase of the life cycle. Although the psychological toll is high, reactions to a diagnosis of prostate cancer vary widely, from a healthy acceptance of both the diagnosis and the treatment to reactions of marked anxiety, depression, hopelessness, and general distress. In one study, nearly one-third of men with prostate cancer in a genitourinary medical clinic had levels of psychological distress that met criteria for a diagnosis of anxiety disorder.²

Several factors influence reactions to a prostate cancer diagnosis, including prior psychological adjustment, social support, economic

resources, and other life changes or events (e.g., loss of spouse, recent or impending retirement).³⁻⁵ However, despite the high prevalence rate, there has been remarkably little systematic research concerning the nature of psychological distress and the prevalence of psychiatric disorders in this population.⁶⁻⁸ Sources of distress commonly noted include sexual dysfunction, urinary incontinence, bowel dysfunction, weakness, fatigue, hot flashes, and pain.⁹⁻¹¹ In addition, many individuals experience profound changes in their mood, irritability, and anxiety due to either the disease or its treatment.^{3,5,12-16}

Although the psychological needs and psychiatric symptoms of men with prostate cancer are important, securing mental health evaluation and treatment for this population has presented difficulties.² Compared with patient assessments, urologists underestimate patient symptoms that cause impairment of quality of life.¹⁷ Oncologists and oncology nurses often are reluctant to ask patients about psychological problems and frequently fail to recognize symptoms of depression, even when they are severe.^{4,18,19} Many elderly men with cancer are reluctant to acknowledge their emotional distress and/or seek treatment because of both embarrassment and stigma. Doctors often learn of their patients' distress from spouses, who also have high levels of distress.^{3,20} Distress also may manifest as complaints of physical symptoms rather than acknowledging the psychological origin of these complaints. Perhaps most commonly, men with prostate cancer express their anxiety through concerns about their prostate specific antigen (PSA) levels. Concern about PSA levels is common and troubling, because the levels herald disease progression. Weeks before their actual tests, men are anxious and sometimes delay testing or request repeated PSA testing to assure that the results are correct.²¹

To improve the recognition and assessment of anxiety related to prostate cancer and PSA levels, we developed a self-report measure, the Memorial Anxiety Scale for Prostate Cancer (MAX-PC). A 24-item scale was designed to tap 3 aspects of prostate-cancer related anxiety: general anxiety related to prostate cancer and treatment, fear of recurrence, and anxiety specifically related to PSA testing. This scale incorporated items from the Fear of Recurrence Scale developed by Kornblith and colleagues^{22,23} and modified items from the Breast Cancer Anxiety Questionnaire developed by Kash and Jacobsen²⁴ as well as new items generated by clinical experts.

The MAX-PC was administered initially to a sample of 66 men with prostate cancer to assess item clarity, ease of completion, and psychological reactions to the content. New items were then generated

from patient feedback on the initial versions of the scale. These items were intended to form three distinct subscales: a Prostate Cancer Anxiety Subscale, a PSA Anxiety Subscale, and a Fear of Recurrence Subscale. Although the reactions to this pilot sample were quite positive, six items were deleted, two items were added, and the wording of two items was modified based on patients' comments concerning lack of clarity of the item.

The current study was designed to provide initial validation for a 24-item measure in a large sample of ambulatory men with prostate cancer. Specifically, we administered the MAX-PC along with several measures to test reliability and validity (concurrent and discriminant). In addition, we assessed patients both before and shortly after learning the results of a PSA test to assess the consistency of the MAX-PC over time and its sensitivity to changing PSA levels.

MATERIALS AND METHODS

Patients were recruited from genitourinary clinics throughout the U.S. These sites all were institutions and group practices that participate in clinical trial research for AstraZeneca Pharmaceuticals (the AstraZeneca Pharmaceutical Research Consortium of Oncology Investigators). No financial support was provided by AstraZeneca to any of the participating investigators for the conduct of this study. All patients were eligible to participate in this study if they were being monitored with regular PSA tests, were older than 18 years, and were English-speaking. All patients were informed of the nature of the study, including relevant risks and benefits, and provided written informed consent. The study was approved by the institutional review boards of Memorial Sloan-Kettering Cancer Center and the AstraZeneca Pharmaceutical Research Consortium.

After patients provided informed consent (usually during the patient's clinic visit just prior to having blood drawn for PSA testing), study participants were given a packet of seven questionnaires and were asked to complete these questionnaires while they waited to see their physician. In addition to the MAX-PC, the measures administered at study entry included the Hospital Anxiety and Depression Scale (HADS), a 14-item self-rated questionnaire that has been tested extensively in cancer populations, with Depression and Anxiety Subscales of 7 items each;²⁵⁻²⁹ the Distress Thermometer, a recently developed visual analogue scale⁴ on which scores range from 0 (no distress) to 10 (extreme distress); the Functional Assessment of Cancer Therapy Scale, Prostate Module (FACT-P), developed by Cella and colleagues,³⁰⁻³² which is a quality-of-life questionnaire that includes a 27-item *core*

quality-of-life measure (the FACT Quality-of-Life Scale [FACT-G]) grouped into four subscales (Physical Well-Being, Social/Family Well-Being, Emotional Well-Being, and Functional Well-Being), and 12 items specific to prostate cancer (FACT-P); the Role Functioning and Sleep Subscales of another quality-of-life measure, the Medical Outcomes Survey (MOS) Short Form 36;³³ the Urinary Function Subscale of the Quality-of-Life in Prostate Cancer measure developed by Litwin and colleagues;⁹ and a brief sociodemographic³⁴ and medical questionnaire (including PSA values from the last 3 tests drawn). After completing the baseline assessment, participants were given another set of questionnaires (the MAX-PC, the HADS, and the Distress Thermometer) with instructions to complete these measures within 1 week after they were informed of their PSA test result (the follow-up assessment). Completed questionnaires were mailed to the data coordinator at each of the participating sites.

Statistical Analyses

Descriptive statistics were used to characterize the sample with regard to demographic and clinical characteristics. Scale properties for the MAX-PC scale were evaluated using several methods, including the coefficient α and the item-total correlation (r) to assess internal consistency, an analysis of individual items to assess the validity and specificity of each item, and test-retest reliability coefficients. Exploratory factor analysis (using a principal components extraction method and varimax rotation) was used to assess the extent to which the scale fit the initially intended three-factor model. Concurrent and discriminant validity was assessed by correlational analyses (i.e., correlation of the MAX-PC with measures of psychological distress and physical functioning). Longitudinal data also were analyzed to ascertain whether changes in MAX-PC scores corresponded to changes in other measures of psychosocial functioning or actual changes in PSA levels.

Sample Characteristics

Three hundred eighty-five men completed the assessment at study entry. The average age of participants was 71.05 years (standard deviation, 9.3 years; range, 40–93 years). The majority of participants were Caucasian ($n = 319$ patients; 86.2%) and were married at the time of participation ($n = 306$ patients; 82.7%) (Table 1). Roughly half of the men in the sample were classified with organ-confined disease ($n = 188$ patients; 54.6%; T1 or T2, N0, and M0), whereas 92 patients (26.7%) had locally advanced disease (T3 or T4, N0, and M0), and 64 patients (18.6%) had metastatic prostate carcinoma (T3 or T4, N1–N3, and M1–M3);

TABLE 1
Demographic and Medical Characteristics

Variable ^a	No. of patients	%
Race		
Caucasian	319	86.2
African American	35	9.5
Other	16	4.3
Marital status		
Married	306	82.7
Single	11	3.0
Divorced, separated, widowed	53	14.3
Education		
Less than high school	46	12.5
High school graduate	84	2.9
Partial college	82	22.3
College or graduate degree	155	42.2
Disease stage		
Organ-confined disease	188	54.6
Locally advanced disease	92	26.7
Metastatic disease	64	18.6
Baseline PSA level		
None detectable	22	6.2
< 2 ng/ml	244	68.9
2–10 ng/ml	56	15.8
> 10 ng/ml	32	9.0
Medical history		
Prostatectomy	177	48.8
Radiation therapy	251	70.5
Seed implants	315	89.5
Orchiectomy	332	94.9
Hormonal therapy	215	61.1
Other chemotherapy	337	95.7

PSA: prostate specific antigen.

^a All demographic data were missing for 15 patients.

these data were missing for 41 patients). The average Karnofsky performance rating for the sample was 96.5, with only 2 patients (0.6%) who had a rating < 70 and 7 patients (2%) who had a rating < 80.

Follow-up data were available for 348 participants, representing 90% of the original sample. The average time between baseline and follow-up assessments was 13.7 days (standard deviation, 10.0 days; median, 12 days; time between assessments was not available for 52 participants). A small (but unknown) percentage of patients returned the Time 2 questionnaire before they learned of their PSA results, which likely attenuated the correlation between changes in PSA levels and changes in MAX-PC scores; however, these questionnaires could not be identified reliably and, thus, were included in the data analysis. Even among questionnaires that were returned after patients learned of their follow-up PSA results, the vast majority of study participants had little change in PSA levels between baseline and follow-up assessments. For the purpose of data analysis, participants were

TABLE 2
Internal Consistency of Total Score and Subscales

Subscale	Original 24-item scale		Modified 18-item scale	
	α	Item-total r	α	Item-total r
Total score	0.89	0.13–0.67	0.89	0.26–0.68
Prostate Cancer Anxiety (Subscale 1)	0.90	0.38–0.72	0.90	0.58–0.71
PSA Anxiety (Subscale 2)	0.56	0.26–0.45	Not modified	—
Fear of Recurrence (Subscale 3)	0.76	–0.08–0.69	0.82	0.59–0.72

α : Correlation α ; r: item total correlation; PSA: prostate specific antigen.

classified with *no change* in their PSA levels if the magnitude of change in PSA levels was < 2 ng/ml in either direction. Of the 385 patients available for this analysis, 278 patients (72.2%) were classified with no change in their PSA level. Only 24 patients (6.2%) had increases ≥ 2 ng/ml in their PSA levels, whereas 83 patients (21.6%) had decreases ≥ 2 ng/ml. The median change in PSA levels was 0, with a range of + 100 to – 107. Because of the presence of extreme scores, these data were converted to ranks for correlational analyses (i.e., Spearman correlation coefficients [r_s]).

RESULTS

Analysis of the Original 24-Item MAX-PC

A reliability analysis of the original 24-item MAX-PC revealed a number of problematic items that led to subsequent modification and shortening of the scale (Table 2). The coefficient α for the total score (24 items) was 0.89, with a median item-total correlation of 0.57 (range, 0.13–0.67). The coefficient α values for the three subscales were 0.90 for the Prostate Cancer Anxiety Subscale, 0.56 for the PSA Anxiety Subscale, and 0.76 for the Fear of Recurrence Subscale. The median item-total correlations for the three subscales were 0.61 (range, 0.38–0.72), 0.44 (range, 0.26–0.45), and 0.54 (range, – 0.08–0.69), respectively.

Results of the initial factor analysis of the 24-item scale generated a somewhat confusing set of results. An analysis of the scree plot suggested both a three-factor model and a five-factor model, yet six factors had Eigen values > 1.0 . However, an inspection of the five-factor and six-factor solutions revealed several single-item factors with seemingly little interpretive significance. Given these findings, coupled with our a priori design of the questionnaire to fit a three-factor model, we chose to analyze the three-factor solution (Table 3).

Analysis of the initial three-factor solution demonstrated considerable consistency with the three

TABLE 3
Rotated Factor Loadings

Item	Initial factor analysis			Modified factor analysis		
	1	2	3	1	2	3
1	0.67	0.09	0.16	0.67	0.05	0.15
2	0.50	0.37	0.15	0.65	0.17	0.07
3	0.77	0.03	0.10	0.72	0.07	0.23
4	0.46	0.33	0.13	—	—	—
5	0.67	0.24	0.01	0.73	0.14	0.08
6	0.54	–0.05	0.05	—	—	—
7	0.68	0.24	0.12	0.67	0.13	0.06
8	0.75	0.03	0.21	0.70	0.11	0.21
9	0.77	0.16	0.13	0.72	0.11	0.16
10	0.72	0.05	0.17	0.60	0.19	0.20
11	0.60	0.36	0.09	0.50	0.32	0.34
12	0.65	0.29	0.00	0.71	–0.01	0.24
13	0.75	0.04	0.25	0.75	–0.02	0.25
14	0.53	–0.01	0.15	—	—	—
15	0.04	0.57	0.20	0.01	0.62	0.29
16	0.30	0.49	0.10	0.18	0.71	0.01
17	0.23	0.59	0.04	0.12	0.67	0.04
18	0.12	0.05	0.76	0.09	0.12	0.82
19	0.07	0.19	–0.67	—	—	—
20	0.39	0.09	0.76	0.25	0.13	0.82
21	0.25	0.19	0.51	0.25	0.00	0.72
22	–0.06	0.00	0.56	—	—	—
23	0.02	0.55	0.25	—	—	—
24	0.32	0.21	0.66	0.31	0.16	0.73

subscales that were supposed to comprise the MAX-PC but with several items that did not load significantly on any factor. Of the 14 items that were supposed to comprise the Prostate Cancer Anxiety Subscale, 13 items had loadings ≥ 0.5 on the first factor, and no items had higher loading on a different factor. Likewise, two of the three PSA Anxiety Subscale items had loadings > 0.5 on the second factor (and the third item loading was 0.49), and five of the seven Fear of Recurrence Subscale items had loadings > 0.5 on the third factor (one item from this subscale had a higher loading on the second factor).

TABLE 4
The Modified 18-Item Memorial Anxiety Scale for Prostate Cancer

YOUR FEELINGS ABOUT PROSTATE CANCER AND PROSTATE SPECIFIC ANTIGEN TESTS

We would like to better understand how patients cope with aspects of their treatment for prostate cancer and the medical tests frequently involved in their care.

I. Below is a list of comments made by men about prostate cancer. Please indicate by circling the number next to each item how frequently these comments were true for you *during the past week*; not at all, rarely, sometimes, often.

	Not at all	Rarely	Sometimes	Often
1. Any reference to prostate cancer brought up strong feelings in me.	0	1	2	3
2. Even though it's a good idea, I found that getting a PSA test scared me.	0	1	2	3
3. Whenever I heard about a friend or public figure with prostate cancer, I got more anxious about my having prostate cancer.	0	1	2	3
4. When I thought about having a PSA test, I got more anxious about my having prostate cancer.	0	1	2	3
5. Other things kept making me think about prostate cancer.	0	1	2	3
6. I felt kind of numb when I thought about prostate cancer.	0	1	2	3
7. I thought about prostate cancer even though I didn't mean to.	0	1	2	3
8. I had a lot of feelings about prostate cancer, but I didn't want to deal with them.	0	1	2	3
9. I had more trouble falling asleep because I couldn't get thoughts of prostate cancer out of my mind.	0	1	2	3
10. I was afraid that the results from my PSA test would show that my disease was getting worse.	0	1	2	3
11. Just hearing the words "prostate cancer" scared me.	0	1	2	3

II. For the next three questions, please indicate how frequently these situations have *EVER* been true for you.

	Not at all	Rarely	Sometimes	Often
12. I have been so anxious about my PSA test that I have thought about delaying it.	0	1	2	3
13. I have been so worried about my PSA test result that I have thought about asking my doctor to repeat it.	0	1	2	3
14. I have been so concerned about my PSA test result that I have thought about having the test repeated at another lab to make sure they were accurate.	0	1	2	3

III. Listed below are a number of statements concerning a person's beliefs about their own health. In thinking about the *past week*, please indicate how much you agree or disagree with each statement: strongly agree, agree, disagree, or strongly disagree. Please circle the number of your answer.

	Strongly agree	Agree	Disagree	Strongly disagree
15. Because cancer is unpredictable, I feel I cannot plan for the future.	0	1	2	3
16. My fear of having my cancer getting worse gets in the way of my enjoying life.	0	1	2	3
17. I am afraid of my cancer getting worse.	0	1	2	3
18. I am more nervous since I was diagnosed with prostate cancer	0	1	2	3

PSA: prostate specific antigen.

Analysis of the Modified 18-item MAX-PC

After reviewing the initial reliability data and factor analysis results as well as the correlations between individual items and measures used to assess concurrent validity (not reported here), a modified and abbreviated version of the original scale was derived

(Table 4). This revised scale omitted 3 of the 14 items from the Prostate Cancer Anxiety Subscale and 3 of 7 items from the Fear of Recurrence Subscale. The three-item PSA Anxiety Subscale was retained in its entirety.

Reliability data for the modified version of the

TABLE 5
Correlations with the Prostate Specific Antigen Anxiety Scale
(Modified 18-item version)

Variable	MAX-PC total score	Prostate cancer anxiety (Subscale 1)	PSA anxiety (Subscale 2)	Fear of recurrence (Subscale 3)
HADS total score	0.52	0.43	0.20	0.53
HADS Anxiety	0.57	0.51	0.21	0.50
HADS Depression	0.31	0.20	0.12	0.43
Distress Thermometer	0.45	0.43	0.08	0.37
Quality of life total	-0.28	-0.24	-0.15	-0.40
Urinary functioning	-0.06	-0.04	-0.05	-0.09
Sleep disturbance	-0.20	-0.15	-0.06	-0.25
Daily activities	0.06	0.06	0.05	0.14
Age	-0.13	-0.19	-0.07	0.03
Education	-0.13	-0.09	-0.01	-0.18
Karnofsky performance	-0.01	0.01	0.09	-0.10

MAX-PC: Memorial Anxiety Scale for Prostate Cancer; PSA: prostate specific antigen; HADS: Hospital Anxiety and Depression Scale.

MAX-PC were slightly better compared with reliability data for the original scale. The coefficient α for the revised 18-item scale was 0.89, with a median item-total correlation of 0.59 (range, 0.26–0.68; see Table 2). The coefficient α for the two modified subscales (Prostate Cancer Anxiety and Fear of Recurrence) were 0.90 (median item-total correlation, 0.65; range, 0.58–0.71) and 0.82 (range, 0.59–0.72), respectively.

Test-retest reliability (for the 18-item scale) was established by comparing MAX-PC scores at the baseline and follow-up assessments (an average of 10 days). Test-retest reliability was 0.89 (95%CI, 0.87–0.91) for the total score, 0.83 (95%CI, 0.79–0.86) for the Prostate Cancer Anxiety Subscale, 0.74 (95%CI, 0.67–0.79) for the PSA Anxiety Subscale, and 0.98 (95%CI, 0.97–0.98) for the Fear of Recurrence Subscale.

Principal components factor analysis of the revised 18-item scale clearly supported the 3-factor model, because the scree plot, Eigen values, and factor loadings all supported the expected 3-factor solution. This solution was highly consistent with the original questionnaire design (Table 3). All 11 items from the Prostate Cancer Anxiety Subscale had factor loadings ≥ 0.5 on factor 1, and 10 items had loadings ≥ 0.60 ; whereas all 3 items from the PSA Anxiety Subscale loaded onto factor 2 with loadings ≥ 0.60 , and the 4 Fear of Recurrence items loaded on factor 3 with loadings > 0.7 .

Concurrent and Discriminant Validity

Total scores on the MAX-PC (revised 18-item version) were correlated significantly with several measures of anxiety that were administered concurrently (Table 5).

Specifically, MAX-PC total scores were correlated highly with HADS total scores ($r = 0.52$; $P < 0.0001$), scores on the Anxiety Subscale of the HADS ($r = 0.57$; $P < 0.0001$), and the Distress Thermometer ($r = 0.45$; $P < 0.0001$). The correlation between MAX-PC total scores and the HADS Depression Subscale, as expected, was lower compared with the correlation observed for the Anxiety Subscale, although this correlation remained significant ($r = 0.31$; $P < 0.0001$). Significant, albeit modest, negative associations also were observed between MAX-PC scores and scores on a measure of sleep quality ($r = -0.20$; $P = 0.0002$) and overall quality of life ($r = -0.28$; $P < 0.0001$).

There was no correlation between MAX-PC scores and absolute PSA levels at baseline ($r_s = 0.02$; $P = 0.69$). In addition, anxiety levels did not differ among participants who did or did not undergo prior prostatectomy ($r = -0.06$; $P = 0.29$). Likewise, there was no association between MAX-PC total scores and scores on measures of overall physical functioning (i.e., Karnofsky performance score: $r = -0.01$; $P = 0.83$; MOS Role Functioning Subscale: $r = 0.06$; $P = 0.25$), or urinary functioning ($r = -0.06$; $P = 0.23$). There was no difference in MAX-PC scores depending on stage of disease ($F[2,338] = 0.58$; $P = 0.56$). However, there were small but statistically significant associations between MAX-PC scores and age ($r = -0.13$; $P = 0.01$) as well as education ($r = -0.13$; $P = 0.01$).

Subscale Characteristics

Analysis of the MAX-PC subscales indicated that the Prostate Cancer Anxiety Subscale appeared to tap anxiety much more specifically than the other subscales, whereas the Fear of Recurrence Subscale was more sensitive to psychological distress broadly defined (Table 5). Both the Prostate Cancer Anxiety Subscale and the Fear of Recurrence Subscale were highly (and comparably) associated with the HADS Anxiety Subscale ($r = 0.51$ and $r = 0.50$, respectively; $P < 0.0001$ respectively) and the distress thermometer ($r = 0.43$ and $r = 0.37$, respectively; $P < 0.0001$). However, the Fear of Recurrence Subscale was correlated highly with the HADS total score ($r = 0.53$; $P < 0.0001$), the Depression Subscale of the HADS ($r = 0.43$; $P < 0.0001$), overall quality of life ($r = -0.40$; $P < 0.0001$), and scores on the measure of sleep disturbance ($r = -0.25$; $P < 0.0001$). Conversely, the Prostate Cancer Anxiety Subscale was not correlated as highly (although all correlations were statistically significant) with any of these measures (HADS Depression Subscale: $r = 0.20$; $P = 0.0002$; quality-of-life measure: $r = -0.28$; $P < 0.0001$; sleep disturbance: $r = -0.15$; $P = 0.004$). The PSA Anxiety Subscale was

TABLE 6
Correlations with Prostate Specific Antigen Anxiety Based on
Longitudinal Analyses (Modified 18-item version)

Variable	MAX-PC total score	Prostate cancer anxiety (Subscale 1)	PSA anxiety (Subscale 2)	Fear of recurrence (Subscale 3)
PSA value ^a	0.13	0.18	0.02	-0.02
HADS total score	0.30	0.28	0.00	0.12
HADS Anxiety	0.39	0.37	-0.02	0.14
HADS Depression	0.09	0.07	0.03	0.06

MAX-PC: Memorial Anxiety Scale for Prostate Cancer; PSA: prostate specific antigen; HADS: Hospital Anxiety and Depression Scale.

^a Spearman correlation coefficients.

associated less clearly with any of the measures administered, although the strongest and only significant associations were with the HADS total score and the HADS subscales.

Longitudinal Analyses

Although we anticipated that patients with rising PSA levels would display more PSA-related anxiety when they were retested, this hypothesis received only limited support (Table 6). Overall changes in PSA levels (calculated as the difference between PSA levels before and after the baseline assessment) were correlated modestly with changes in MAX-PC scores (the follow-up score minus the baseline score: $r_s = 0.13$; $P = 0.02$). An analysis of the three MAX-PC subscales indicated that the Prostate Cancer Anxiety Subscale was much more sensitive to changes in PSA levels compared with the other two subscales. There was a significant correlation between changes in scores for the Prostate Cancer Anxiety Subscale and PSA changes ($r_s = 0.18$; $P = 0.002$), but there was no correlation between PSA changes and scores for the other two subscales (PSA Anxiety Subscale: $r_s = 0.02$; $P = 0.67$; Fear of Recurrence Subscale: $r_s = -0.02$; $P = 0.72$).

Significant associations also were found between changes in the MAX-PC score and the other measures of anxiety and psychological distress. Changes in the MAX-PC total score were associated significantly with changes in the HADS total score ($r = 0.30$; $P < 0.0001$) and with changes in the HADS Anxiety Subscale ($r = 0.39$; $P < 0.0001$). However, there was no significant correlation between changes in the HADS Depression Subscale and MAX-PC total scores ($r = 0.09$; $P = 0.09$). The Prostate Cancer Anxiety Subscale of the MAX-PC also appeared to be more sensitive to changes over time compared with the other two subscales, with significant correlations between this subscale and the HADS total score ($r = 0.28$; $P < 0.0001$) and the HADS

Anxiety Subscale ($r = 0.37$; $P < 0.0001$), but not the HADS Depression Subscale ($r = 0.07$; $P = 0.20$). The correlations between changes in the HADS total scores and subscales and the other two MAX-PC subscales were considerably smaller and were largely nonsignificant (Table 6).

DISCUSSION

The MAX-PC was designed to provide a brief, effective method for detecting anxiety in men with prostate cancer. This study, which represents a first attempt at providing validation for the MAX-PC, demonstrated considerable support for the utility of this measure, albeit in a modified and somewhat abbreviated form. Based on data from a large, representative sample drawn from across the U.S., we observed a high degree of reliability for the MAX-PC (i.e., internal consistency and test-retest reliability) as well as concurrent and discriminant validity. We observed substantial correlations between the MAX-PC and measures of other anxiety and distress, lower (but still significant) correlations with measures of depression and sleep disturbance, and no correlation with measures of urinary functioning, physical functioning, or other medical variables that should not necessarily correlate with anxiety (e.g., PSA level and disease stage).

The MAX-PC was designed to assess three different aspects of prostate-related anxiety, including anxiety related to prostate cancer in general (the Prostate Cancer Anxiety Subscale), anxiety specifically focused on PSA testing (the PSA Anxiety Subscale), and fears of cancer recurrence (the Fear of Recurrence Subscale). Factor analysis clearly supported the anticipated 3-factor model, with all items (in the modified 18-item scale) loading on the intended factors. Associations with measures of concurrent and discriminant validity revealed an interesting pattern of differences across the three subscales. The Prostate Cancer Anxiety Subscale appeared to tap anxiety much more specifically than the other factors (higher correlations with measures of anxiety and lower correlations with measures of depression, sleep disturbance, quality of life, etc.). The Fear of Recurrence Subscale, conversely, appeared to tap psychological distress more generally, because correlations with depression and quality of life were considerably higher, almost as high as the correlations with measures of anxiety. Empirical support for the PSA Anxiety Subscale, however, was somewhat weaker, leading us to revise the wording of these questions for future applications of the scale (described further below).

Results from the longitudinal component of the study were somewhat more difficult to interpret. Patients completed the study instruments shortly before

they had blood drawn for their PSA test and again after they learned the results of that test (typically about 2 weeks later). We observed a significant (although quite modest) correlation between changes in PSA levels and changes in MAX-PC scores, as expected, particularly on the Prostate Cancer Anxiety Subscale (changes in PSA Anxiety Subscale and Fear of Recurrence Subscale scores were not associated with changes in PSA levels). However, as noted above, a small percentage of patients returned the Time 2 questionnaire before they learned of their PSA results, which likely decreased our ability to find significant changes over time (i.e., attenuating the correlation between changes in PSA levels and changes in MAX-PC scores). These correlations also may have been more modest than anticipated, because the patients demonstrated little change in PSA levels (75% of patients had no substantial change in PSA level). Thus, although we anticipated that anxiety levels would change substantially over time because of changing medical status, this group of patients may be described more accurately as medically stable, supporting our use of longitudinal data for establishing test-retest reliability.

Although the results based on our original 24-item scale certainly were encouraging, several items were eliminated after preliminary analyses indicated that they were either unnecessary or ineffective at capturing the intended construct. The resulting 18-item scale appears to have even stronger empirical support compared with our original scale, particularly given the importance of brevity in clinical research. We also chose, on the basis of these analyses, to change the wording of the three items that comprise the PSA Anxiety Subscale. These items, which originally were conceived in a behavioral framework (e.g., *Have you ever delayed going for your next PSA test because you were too anxious about it?*), rarely were endorsed by our sample (hence the low reliability and validity data for this subscale). In light of this observation, we elected to reword these items to reflect (as noted in Table 4) an attitudinal framework (e.g., *Have you ever considered delaying a PSA test because you were too anxious about it?*) in hopes of increasing the applicability for most patients. Although the impact of this change in wording is unknown, we anticipate improved reliability and validity data for this subscale.

Despite the strong initial support for the overall MAX-PC in terms of both reliability and validity, the current results are tempered by several methodological limitations. First, although we attempted to stratify recruitment to include equal proportions of patients with early disease and advanced disease, the majority of patients had organ-confined or locally advanced disease and stable PSA levels. Hence, it is unclear how

the scale properties may differ in a population with more advanced disease. Certainly, the possibility of observing changes in anxiety as disease status changes is more likely in a population in which the disease status actually is changing. Perhaps more importantly, we anticipate that the MAX-PC (and the Fear of Recurrence Subscale in particular) may be more useful in differentiating general anxiety from anxiety specific to prostate cancer in a population of acutely ill patients. Nevertheless, further research using the MAX-PC will be needed to understand the utility of this scale more fully.

A second significant issue in terms of our validation data concerns the lack of any psychiatric assessment of the patients studied. Without a clinical diagnosis, it is not possible to determine which patients may meet the criteria for a diagnosis of an anxiety disorder. Thus, we are unable to establish *cut-off scores* to identify patients who may benefit from a referral for psychiatric consultation and/or antianxiety medications. Again, further research will be needed to assess the sensitivity and specificity of the MAX-PC using various cut-off scores.

Despite these limitations, we believe the MAC-PC represents a useful mechanism for identifying and quantifying anxiety in men with prostate cancer. This growing population has long been difficult to engage in psychiatric/psychosocial interventions, although these patients are subject to much psychological distress as a result of both diagnosis and treatment of their disease. The ability to rapidly screen and identify patients who may be experiencing significant anxiety certainly is needed and may facilitate clinical research efforts aimed at treating these troubling symptoms and minimizing the impact of anxiety on overall quality of life for men with prostate cancer.

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SF-12v2TM Health Survey

(SF-12 v2 Standard, US Version 2.0)

To be completed by the PATIENT

Identification Number

Event

Directions: This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities. If you need to change an answer, completely erase the incorrect mark and fill in the correct circle. If you are unsure about how to answer a question, please give the best answer you can.

Today's Date (MM/DD/YY)

		/			/		
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Shade circles like this:

Not like this:



Mark only one answer for each question.

Please do not mark outside the circles or make stray marks on the questionnaire.

	Excellent	Very Good	Good	Fair	Poor
01. In general, would you say your health is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
02. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

03. Climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
04. Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

05. Were limited in the kind of work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

06. Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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07. Did work or activities less carefully than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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	Not at all	A little bit	Moderately	Quite a bit	Extremely
08. During the <u>past 4 weeks</u>, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
09. Have you felt calm and peaceful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. Did you have a lot of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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11. Have you felt downhearted and depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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12. During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting friends, relatives, etc.)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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