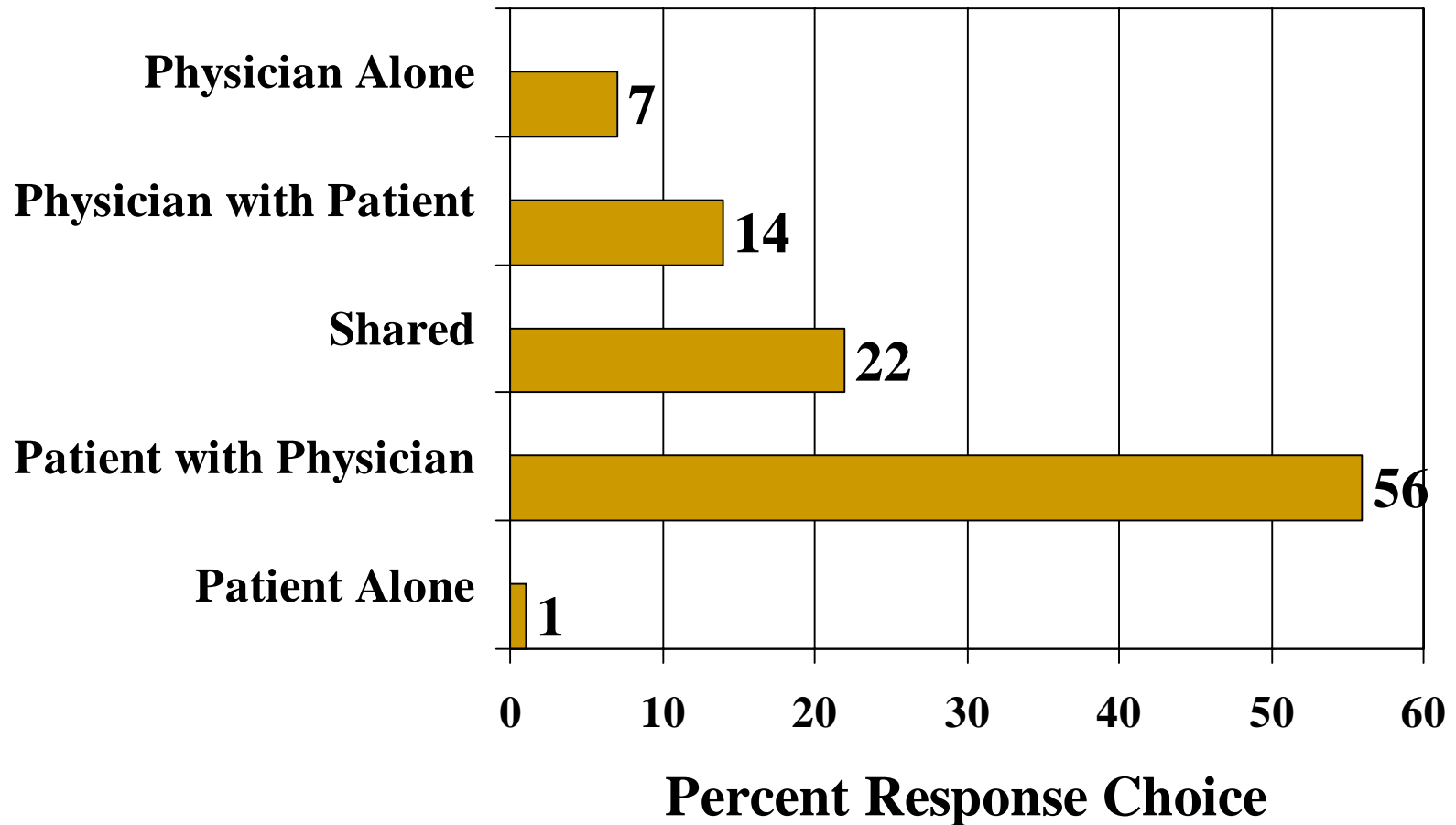

Improving decision making in prostate cancer care

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When is greater patient participation needed in decisions about cancer care?

- Multiple treatment alternatives
 - No treatment is clearly superior
 - Treatments differ in characteristics and outcomes
 - Trade offs must be made between treatment benefits and costs
-

Do men with localized prostate cancer want to participate in treatment decisions?



(Knight et al., Society of Medical Decision Making, 2004)

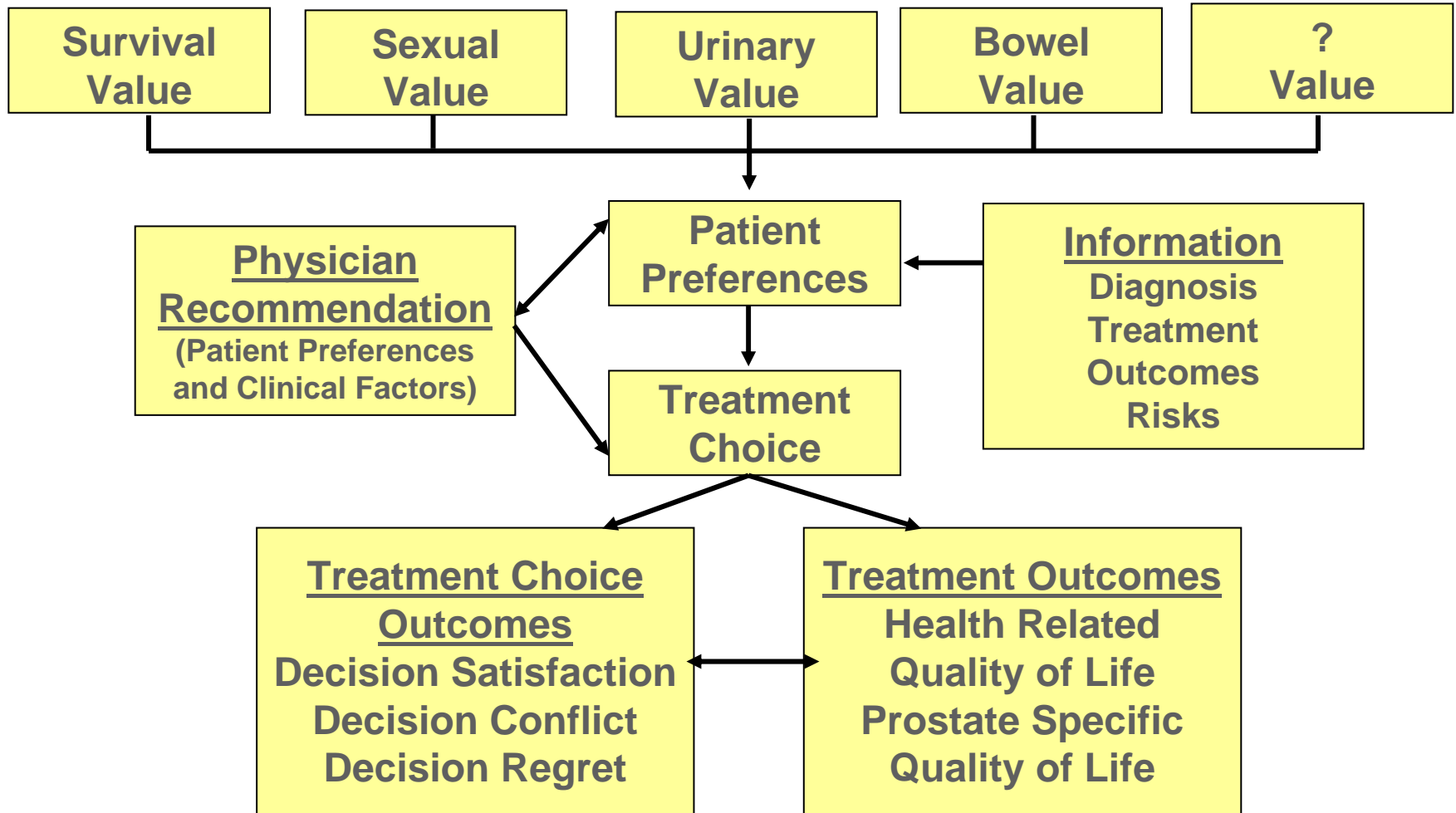
Do cancer clinicians understand patient needs and goals for treatment?

- Patients want their goals and values taken into account in treatment decision making (Knight et al., Society of Medical Decision Making, 2003)
 - But physicians and patients have different goals for treatment (Crawford et al., Urology, 1997)
 - Further, physicians may not always understand the values of their patients (Bennett et al., Eur Urol, 1997, Elstein et al., Health Expectations, 2004, Elstein et al., Health Psychology, 2005)
 - How can patient goals and values be incorporated into treatment decisions?
-

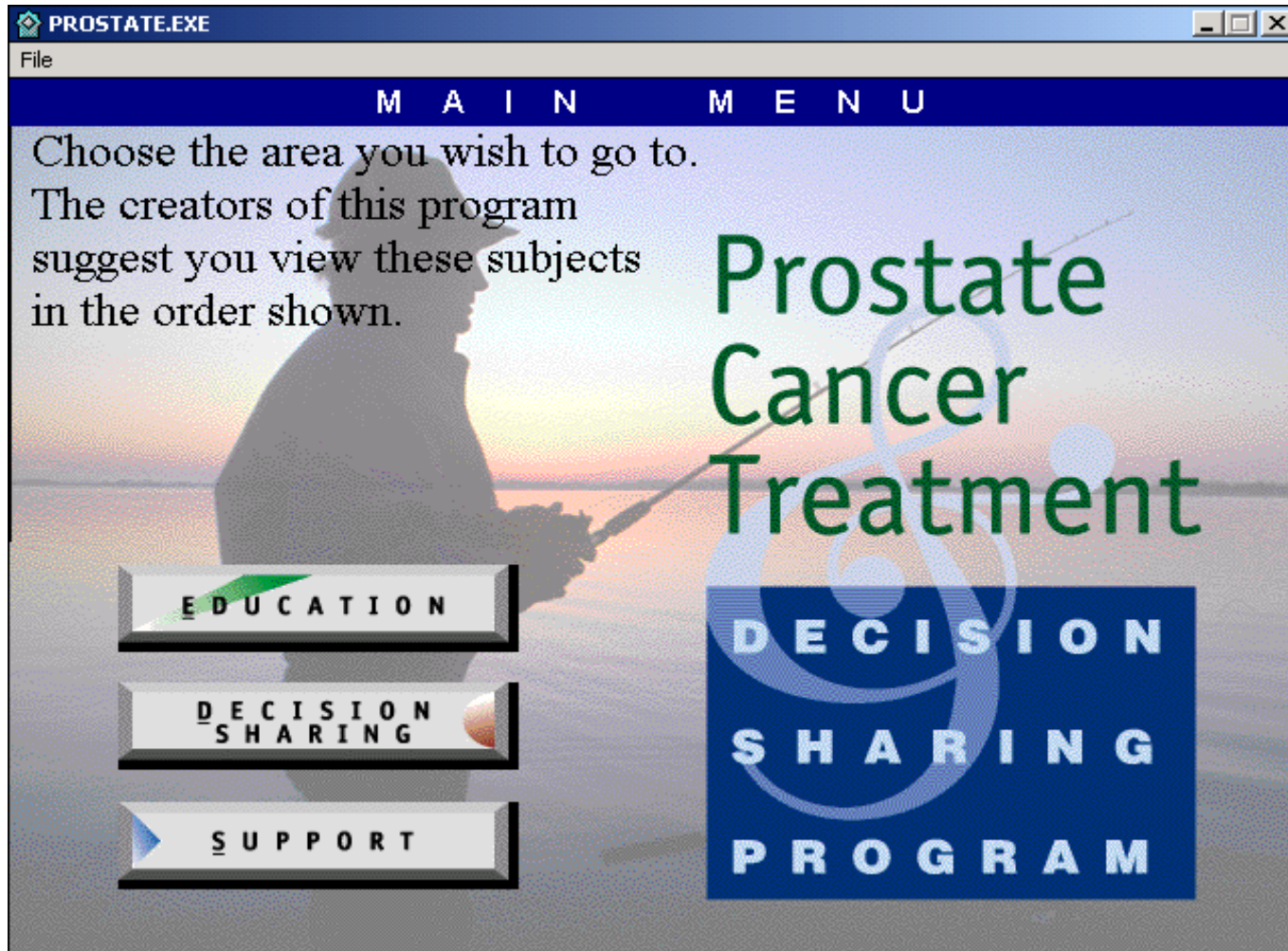
Shared decision making

- Information
 - Health condition
 - Treatments
 - Potential Risks and Benefits
 - Costs
 - Assessment of patient values and goals
 - What is important?
 - What risks are acceptable?
 - What are the trade offs?
 - Discussion of patient values and goals
-

Conceptual Model



Interactive values assessment/education



Values assessment

PROSTATE.EXE

File

DECISION SHARING MENU

15. How would you feel about losing control over urinating?

1 I could not deal with any loss of control over urinating

2 I would not mind losing some control for a few months

3 I would not mind losing some control forever

4 I would accept any loss of control, for any period of time, if it was necessary to treat my cancer

QUIT MAIN MENU DICTIONARY ◀ BACK NEXT ▶

Results

- Patients were highly satisfied with the program
- Two-thirds were able to select a preferred treatment based on the information presented in the program

Results

- Only 67% of patients who selected a treatment actually received the preferred treatment
- Low literacy patients had lower prostate cancer knowledge after program than those with high literacy

Potential weaknesses...

- Low literacy patients helped less
 - Preference assessment not reliable or valid
 - Lack of clinician acceptance
-

Veterans Quality of Life by Education

TABLE 2

Health-Related Quality of Life Mean Scores at 6 Months Posttreatment by Education Controlling for Patient Sociodemographic Characteristics*

Characteristic	<HS	HS	Some college	BA+	ANOVA P
Physical functioning	46.22 (29.24)	62.50 (26.83)	60.44 (30.03)	73.65 (25.82)	<.01
Role physical	20.95 (30.34)	45.24 (45.28)	31.45 (42.80)	58.65 (42.98)	<.01
Role emotional	46.49 (46.85)	70.63 (41.78)	70.00 (40.45)	85.90 (34.22)	<.01
Vitality	45.68 (23.33)	53.05 (23.29)	50.94 (21.38)	58.75 (25.41)	.15
Mental health	67.08 (17.59)	75.05 (14.76)	73.35 (24.02)	79.71 (17.86)	.05
Social function	60.00 (26.43)	72.50 (27.03)	66.53 (30.51)	78.50 (27.13)	.05
Bodily pain	54.56 (27.17)	64.11 (28.39)	58.47 (28.48)	63.75 (24.59)	.38
General health	43.75 (19.61)	63.36 (20.93)	63.96 (27.46)	62.99 (21.22)	<.01
Physical component summary score	32.88 (9.32)	39.75 (11.64)	38.83 (12.53)	41.44 (10.64)	0.02
Mental component summary score	46.51 (11.00)	50.5 (9.89)	50.01 (11.76)	55.30 (10.32)	.03

<HS indicates less than a high school education; HS, high school education or equivalent; BA+, Bachelor's Degree or more education; ANOVA, analysis of variance.

Means are shown for the SF-36 administered at 6 months post-treatment. Standard deviations are shown in parentheses. SF-36 subscale scores range from 0 to 100 with higher scores representing better health-related quality of life. SF-36 Physical Component Summary and Mental Component Summary scores are derived using norm-based scoring where higher scores represent better health-related quality of life (HRQOL).

* Time of HRQOL assessment, age, ethnicity, annual household income.

(Knight et al., Cancer, 2007)

Values assessment/physician feedback

Table 3 | Patient Utilities for Health States

Patient Number	Health States					Utility Consistency	
	< 70 Years of Age	Impotence and Incontinence	Impotence	Incontinence	Watchful Waiting		Current Health
1		1.0	1.0	1.0	1.0	1.0	No gamble
2		0.99	0.97	0.93	0.5	1.0	Inconsistent
3		0.75	0.72	0.5	0.01	1.0	Inconsistent
4		1.0	1.0	1.0	1.0	1.0	No gamble
5		0.03	0.03	0.07	0.82	1.0	Consistent
6		1.0	1.0	1.0	1.0	1.0	No gamble
7		0.96	0.74	0.93	0.5	0.93	Inconsistent
> 70 Years of Age	Impotence and Incontinence	Impotence	Incontinence	Watchful Waiting	Current Health	Utility Consistency	
8		1.0	1.0	1.0	1.0	1.0	No gamble
9		0.63	0.5	0.51	1.0	1.0	Inconsistent
10		0.76	1.0	0.69	0.71	0.99	Inconsistent
11		1.0	1.0	1.0	0.5	1.0	No gamble*
12		0.94	0.5	0.99	0.57	0.99	Inconsistent
13		0.95	0.95	0.94	0.97	0.97	Inconsistent

*Patient took gamble to avoid health state of watchful waiting, but not the health states with side effects or of current health.

(Knight et al., Clinical Prostate Cancer, 2002)

Results

- 4 of 13 patients unwilling to take any risk to avoid side effects
- 7 of 13 patients obtained logically inconsistent scores
- 1 of 13 patients obtained logically consistent scores and were willing to complete the gamble

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Prostate Cancer

Whether you are thinking about being tested for prostate cancer or are choosing a treatment, prostate cancer—like any cancer—can be a frightening subject.

But unlike other cancers, prostate cancer is usually slow growing, and may not ever cause symptoms or make a man feel ill. This means that testing and treatment for prostate cancer have different pros and cons than testing and treatment for other cancers.

Learning about your choices will help you work together with your doctor to decide what is right for you.

Medical Editor

- [Michael J. Barry, MD](#)

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I don't worry too much about this uncertainty matter. That, to me, is off in the blue somewhere. All life is a question mark. You don't know what's around the next corner. But I want to enjoy what I've got right now.
—Glen O.

Printer-Friendly Version

Surgery

Surgery: Radical Prostatectomy

Before removing your prostate, your surgeon may remove the lymph nodes in the area of the prostate.

This is done to check whether cancer has spread to them. Lymph nodes are the filter systems of our bodies. Checking the lymph nodes is usually not necessary for cancers with a low risk of having spread already, based on the PSA, digital rectal exam, and Gleason score.

There are two main types of surgery to remove the prostate: **standard radical prostatectomy** and **laparoscopic radical prostatectomy**. In either procedure, the surgeon removes the entire prostate gland. A standard radical prostatectomy is done using one incision into the lower abdomen and takes about 2 to 5 hours.



I decided to have surgery, which was the best because the cancer had not metastasized. It had not spread. It was in a specific location, and the option was, take it out.
—Harry H., chose surgery

Use this worksheet to help you make your decision. After completing it, you should have a better idea of how you feel about choosing between prostatectomy or radiation therapy. Discuss the worksheet with your doctor.

Circle the answer that best applies to you.

My heart condition may mean that I should not have surgery.	Yes	No	NA*
It is important to me that I can continue to be sexually active.	Yes	No	Unsure
Radiation therapy will fit into my busy life, and I can continue to work without needing to take a lot of days off.	Yes	No	NA
My doctor says my cancer will probably not spread outside of my prostate in the next 10 to 15 years.	Yes	No	Unsure
I may be too old to have major surgery.	Yes	No	Unsure
I'm concerned that if I have radiation therapy, I may never regain my ability to have an erection.	Yes	No	NA
Surgery might keep me from my normal activities for too long a time.	Yes	No	Unsure
I am willing to put up with urinary leakage if surgery will mean the cancer is gone and won't come back.	Yes	No	Unsure
I expect to live longer than 10 more years.	Yes	No	Unsure

Continuing questions about preference assessments...

- Little information on the methods used to develop preference measures—**Are all relevant domains of values included?**
 - Absence of documentation on the reliability and validity of preference assessments
 - **Are the measurements consistent over time if preferences do not change?**
 - **Do the measures predict what men want in their prostate cancer treatment?**
-

Characteristics of a Strong Measure of Patient Preferences

- Comprehensive patient considerations
 - Strong psychometric properties
 - Consistent over time
 - Related to recommendations and outcomes
 - Appropriate for all educational backgrounds
 - Feasible in busy clinic settings
-

What are possible contributions of improved patient preference assessment?

- Clarification of individual differences in decision making
 - Understanding of how preferences may be constructed over time
 - Improved patient-centered care
 - Strengthened patient/physician relationship
-

How wide a range of values need to be considered?

- Assessments of patient goals for localized prostate cancer treatment typically have focused on well defined, clinically-derived attributes (e.g., sexual, urinary, and bowel function) (e.g., Albertsen et al., JUrol, 1998)
 - However, others have identified a wide range of patient concerns that are difficult to integrate in structured approaches to decision making (e.g., self-esteem, masculinity) (e.g., Bokhour et al., JGIM, 2001)
-

What values are important in prostate cancer treatment decisions?

- 75 men diagnosed with localized prostate cancer recruited for participation in focus groups
- Thirteen groups conducted; Each was homogenous in ethnicity (i.e., AA, CA) and primary treatment (i.e., radical prostatectomy, brachytherapy, external beam radiation therapy, watchful waiting)
- Two experienced moderators were matched to the groups by gender and ethnicity; moderators were trained in the specific study methods

Initial schema for coding

Urinary and Sexual Function

Pain/Discomfort/Other Symptoms

Survival Concerns

Treatment Characteristics

Treatment Convenience

Impact of Prostate Cancer on Responsibilities

Impact of Prostate Cancer on Relationships

Impact of Prostate Cancer on Self-perceptions

Content coding

- Two independent coders were trained in using the schema and their initial coding was reviewed and revised by two investigators experienced in qualitative analysis
 - A third coding of the transcripts was conducted by the two independent coders and discrepancies were resolved through discussion and consensus with two investigators experienced in qualitative analysis
 - NVivo software was used to assist in the management of the data
-

Theme	N	Example
Survival	182	Anybody who is diagnosed with that I guarantee you the next thing they think of is death.
Sexual Function	76	...I'm pretty much sexually inactive.
Urinary Function	79	I hate to say it but I just don't see myself wearing diapers for being incontinent..."
Bowel Function	13	...I couldn't contain my bowel movements. I'm going down the freeway and I've got to go...

Theme	N	Example
Treatment Characteristics	115	...I kept wanting to go through radiation because I didn't want to be cut on.
Other Symptoms	75	...then you're going through the change like women go through. Hot flashes and all of that...
Responsibility	16	I wouldn't be able to take care of my wife because I would have been held down because of surgery
Relationships	31	...hey I'm not married ...and now if you fall in love in two months you are not going to be ready to have a family.
Self-esteem	31	We still want to maintain ourselves as we had been...an ego thing...

Values important in prostate cancer decisions

Urinary Function

Sexual Function

Survival

Anxiety about Mortality
Recurrence Concerns

Treatment Characteristics

Invasiveness
Convenience

**Pain/Discomfort
Other Symptoms**

Relationships

Responsibilities
Work/Family

Self-Esteem
Self-Image/Masculinity

Individual interviews

- Individual interviews (n=20) were conducted to explore in greater depth the themes identified in the focus groups
- During the interviews, the men were asked to complete a forced choice task
 - Circle around the category that is most important/line through the least important category

~~Urinary Function~~
Survival
Important Relationships

Individual interview results

- 58% of the men consistently evaluated concerns about relationships, responsibilities, or self-esteem as being more important than urinary or sexual function
 - About a quarter of the men considered relationships, responsibilities, or self-esteem to be more important than survival concerns
-

Conclusions

- This study based on extensive patient input suggests that the conceptual framework for understanding men's preferences for prostate cancer treatment be expanded to incorporate a broader range of decision making considerations
 - This work points to the need for health services researchers to develop theoretical models and measurement systems that include psychological and social context in understanding patient goals and values
-

Values Insight and Balance Evaluation Scales (VIBES)

- Consists of sixty six items organized in three sections
 - In each section eight subscales are represented
 - Sections include three types of judgments:
 - Importance
 - Coping
 - Best/worst
 - Current studies underway to evaluate reliability and validity
-

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