

Appendix 1 – Patient Version - The Development of a Survey to Examine the Effect of Prostate Cancer Treatment on the Patient's and Partner's Sexual Well-being.

PATIENT VERSION
**The Development of a Survey to Examine the Effect of Prostate Cancer Treatment
on the Patient's and Partner's Sexual Well-being**

Sexual status

I. Foreplay

1. Did you use foreplay to enhance your sexual activity before your prostate cancer treatment?
| Yes | No
If Yes, please specify _____

2. How has your sexual relationship with regard to foreplay changed since treatment?
| More foreplay | The same | Less foreplay

3. What are you doing differently? _____

4. Over the last 4 weeks, does foreplay help?
| Yes | No
If Yes, whom particularly to
| You | Partner | Both

5. What advice would you give to other couples? _____

II. Sexual desire (libido)

1. Over the last 4 weeks, are you happy with your level of sexual desire or interest?
| Very much | Much | Moderate | Little | Very little or none at all

2. Over the last 4 weeks, are you happy with the level of sexual desire or interest of your partner?
| Very much | Much | Moderate | Little | Very little or none at all

3. Over the last 4 weeks, do you lose urine during sex or ejaculation?
| Yes | No (if so, please go to question # 6 of this section)
If Yes, does this bother? | You | Her | Both

4. Has any loss of urine affected your willingness to engage in sexual relations?
| Yes | No | remains the same

5. Do you feel that your loss of urine has affected your partner's willingness to engage in sexual relations?
| Yes | No | remains the same

6. Has the appearance of your penis changed with treatment of prostate cancer?
| Yes | No
If yes, how? _____

7. Does it bother you or somehow reflect on your sexual behavior?
| Yes | No
If yes, how? _____

8. Does your partner feel the appearance of your penis after prostate cancer treatment has changed their sexual behavior?
| Yes | No
If Yes, how _____

III. Erection

1. Over the last 4 weeks, how would you rate the level of your erection ("turn on") during sexual activity or intercourse?
| Very high | High | Moderate | Low | Very low or none at all

2. Before prostate cancer treatment on average how many times per month did you or our partner initiate sex?

| 1 | 2 | 3 | 4 | Equal or more than 5

3. Over the last 4 weeks, on average how many times have you or your partner initiated sex?

| 1 | 2 | 3 | 4 | Equal or more than 5

4. Do you consider yourself potent (e.g. able to have an erection sufficient for intercourse)?

| Yes | No | Partially

Otherwise (please specify) _____

5. What medical methods did you use to restore or improve your erection after treatment? (please circle all that apply)

| Medications (Viagra, Cialis, Levitra, Muse- please circle which one(s))

| Penile injection (Caverject)

| Vacuum Erection Device

| Penile Prosthesis

| Other (please list) _____

6. Does the use of this drug or therapy interrupt the "naturalness" of the sexual act?

| Yes | No | Otherwise (please specify): _____

7. Were any alternative methods used to restore or improve your erectile dysfunction?

(e.g. herbals, erotic aids, nude videos, etc.) If yes, please list them.

8. What was your level of satisfaction with any of the methods you tried or used to restore or augment your sexual function after prostate cancer treatment? Please list each method that was tried, as well as your level of satisfaction with it.

9. Would you recommend any of these methods to couples with similar problems?

Are there any methods you would not recommend to others?

IV. Orgasm

1. Has your experience of orgasm changed following prostate cancer treatment?

| Yes | No

If Yes, how _____

2. Has your partner's experience of orgasm changed following prostate cancer treatment?

| Yes | No

If Yes, how _____

3. Over the last 4 weeks, how satisfied are you with your ability to reach orgasm during sexual activity or intercourse after prostate cancer treatment?

| No sexual activity

| Very satisfied

| Moderately satisfied

| About equally satisfied and dissatisfied

| Moderately dissatisfied

| Very dissatisfied

4. Over the last 4 weeks, how satisfied are you with your partner's ability to reach orgasm during sexual activity or intercourse?

| No sexual activity

| Very satisfied

| Moderately satisfied

| About equally satisfied and dissatisfied

| Moderately dissatisfied

| Very dissatisfied

V. Ejaculation

1. Has the nature of your ejaculation changed following prostate cancer treatment?

| Yes | No

If Yes, please specify how:

| No ejaculation | Minimal fluid | Loses urine | Other

Please specify: _____

2. Does the lack of an ejaculate cause any problems?

| Yes | No | Not applicable

If Yes, how _____

Emotional status

1. Did/do you have any mood disorders after prostate cancer treatment?

| No | Anxiety | Negative affect | Depression | Other

Please specify: _____

If so, did/does it affect your sexual status?

| Yes | No | Sometimes

If Yes, to what extent?

| Very high | High | Moderate | Low | Very low or none at all

Relationship

1. How important was the sexual relationship in the overall personal relationship with your partner before prostate cancer treatment?

| Not important | Somewhat important | Very Important

2. How important is the sexual relationship in the overall personal relationship with your partner after prostate cancer treatment?

| Not important | Somewhat important | Very Important

3. How would you rate your overall sexual relationship with your partner?

| Poor | Satisfactory | Good | Very good | Excellent

4. How would you describe your partner's attitude toward your sexual relationship?

| Supportive | Unsure | Unsupportive

5. How have the non-sexual components of your relationship (e.g. bonding, quality time, snuggling) changed since your treatment?

| More | The same | Less

Please give examples: _____

6. Has your relationship with your partner changed since prostate cancer treatment?

| Yes | No

If Yes, please explain how _____

7. What advice would you give to other couples? _____

Self image

1. How has your sense of your male self-esteem changed since your prostate cancer treatment?

| Increased | Unchanged | Decreased

2. How would you describe your sense of your physical appearance since your prostate cancer treatment?

| Satisfied | Unchanged | Unsatisfied

3. How would you describe your partner's sense of your physical appearance since your treatment?

| Satisfied | Unchanged | Unsatisfied

4. How would you describe your overall attitude regarding your sexual function since your prostate cancer treatment?

| Completely satisfied

| Mostly satisfied

- | Fair
- | Mostly unsatisfied
- | Completely unsatisfied

5. How would you describe your overall attitude regarding her sexual function since prostate cancer treatment?

- | Completely satisfied
- | Mostly satisfied
- | Fair
- | Mostly unsatisfied
- | Completely unsatisfied

Partnership quality

1. Do you have a good partnership? | Yes | No
2. Is your relationship with your partner very stable? | Yes | No
3. Is your partnership strong? | Yes | No
4. Does your relationship with your partner make you happy? | Yes | No
5. Do you really feel like part of a team with your partner? | Yes | No
6. Could you please rate the degree of your happiness in your partnership:
 -10 _____ 0 _____ 10

very unhappy neutral perfectly happy

7. How often have you and your partner seriously discussed ending your relationship?
 | Never | Once-Twice | More often
 8. Do changes in your sexual function or your partner's sexual function affect your serious consideration to end your relationship?
 | Yes | Somewhat | No | Not applicable
- If Yes or Somewhat, please explain _____

Support

1. How have you been supported by your partner after your prostate cancer treatment? _____
 2. Did your partner's support help you to restore your sexual activity after your prostate cancer treatment?
 | Yes | No
- If Yes, did it also help your partner as well in her self confidence after your cancer treatment?
 | Yes | Somewhat | No
3. Were any other particular coping mechanisms helpful?
 | support groups | psychological support | advice from other patients | other: _____

Concluding questions

1. Are you ultimately pleased with your prostate cancer treatment choice?
 | Yes | No
 Please specify _____
2. Do you feel that the side effects (change in erection or sexual function, loss of urine, etc.) from your prostate cancer treatment were what you expected?
 | Yes | No
 Please explain: _____
3. Would you want to choose with your partner the same treatment for prostate cancer if it were done again (please explain)

4. What would you like to have known before treatment that you know now? _____
5. What advice would you give to other patients considering this form of prostate cancer treatment? _____

Appendix 2 – PARTNER VERSION – The Development of a Survey to Examine the Effect of Prostate Cancer Treatment on the Patient’s and Partner’s Sexual Well-being.

PARTNER VERSION
The Development of a Survey to Examine the Effect of Prostate Cancer Treatment on the Patient’s and Partner’s Sexual Well-being

Sexual status

I. Foreplay

1. Did you use foreplay to enhance your sexual activity before your partner’s prostate cancer treatment?
Yes No
If Yes, please specify _____

2. How has your sexual relationship with regard to foreplay changed since his treatment?
More foreplay The same Less foreplay

3. What are you doing differently? _____

4. Over the last 4 weeks, does foreplay help?
Yes No
If Yes, whom particularly to
You Him Both

5. What advice would you give to other couples? _____

II. Sexual desire (libido)

1. Over the last 4 weeks, are you happy with your level of sexual desire or interest?
Very much Much Moderate Little Very little or none at all

2. Over the last 4 weeks, are you happy with the level of sexual desire or interest of your partner?
Very much Much Moderate Little Very little or none at all

3. Over the last 4 weeks, did your partner lose urine during sex or ejaculation?
Yes No (if so, please go to question # 6 of this section)
If Yes, does this bother? You Him Both

4. Has any loss of urine by your partner affected your willingness to engage in sexual relations?
Yes No remains the same

5. Has the appearance of your partner’s penis changed with treatment of prostate cancer?
Yes No
If yes, how? _____

6. Does it bother you or somehow reflect on your sexual behavior? Yes No
If yes, how? _____

7. Does the change in his penile appearance bother him or changed his sexual behavior?
Yes No
If Yes, how _____

III. Arousal (lubrication)

1. Over the last 4 weeks, how would you rate the level of your arousal (“turn on”) during sexual activity or intercourse?
Very high High Moderate Low Very low or none at all

2. Over the last 4 weeks, how would you rate the level of erection (“turn on”) of your partner during sexual activity or intercourse?
Very high High Moderate Low Very low or none at all
Has this changed after prostate cancer treatment? _____

3. Before prostate cancer treatment on average how many times per month did you or your partner initiate sex?
1 2 3 4 Equal or more than 5

4. Over the last 4 weeks, on average how many times have you or your partner initiated sex?
1 2 3 4 Equal or more than 5
5. Would you consider your partner to be potent (e.g. able to have an erection sufficient for intercourse)?
Yes No Partially
Otherwise (please specify) _____
6. What medical methods are/were used by your partner to restore or improve his erection after prostate cancer treatment? (please circle all that apply)
Medications (Viagra, Cialis, Levitra, Muse- please all applicable)
Penile injection (Caverject)
Vacuum Erection Device
Penile Prosthesis
Other (please list): _____
7. What was your level of satisfaction with any of the above-mentioned methods your partner tried/used to restore or augment his sexual function after prostate cancer treatment? Please list each method that was tried, as well as your level satisfaction beside it. _____
8. Does the use of this drug or therapy interrupt the "naturalness" of the sexual act?
Yes No Otherwise (please specify): _____
9. Were any alternative methods used to restore or improve your partner's erections or enhance his sexual activity? (e.g. herbals, erotic aids, nude videos, etc.) If yes, please list them.

10. What advice would you give to other couples? _____

IV. Orgasm

1. Has your experience of orgasm changed following your partner's prostate cancer treatment?
Yes No
2. Has your partner's experience of orgasm changed following his prostate cancer treatment?
Yes No
If Yes, how _____
3. Over the last 4 weeks, how satisfied were you with your ability to reach orgasm during sexual activity or intercourse?
No sexual activity
Very satisfied
Moderately satisfied
About equally satisfied and dissatisfied
Moderately dissatisfied
Very dissatisfied
4. Over the last 4 weeks, how satisfied were you with your partner's ability to reach orgasm during sexual activity or intercourse?
No sexual activity
Very satisfied
Moderately satisfied
About equally satisfied and dissatisfied
Moderately dissatisfied
Very dissatisfied

V. Ejaculation of your partner

1. Has the nature of your partner's ejaculation changed following prostate cancer treatment?
Yes No
If Yes, please specify how
No ejaculation Minimal fluid Loses urine Other _____

2. Does the lack of an ejaculate cause any problems?

Yes No Not applicable

If Yes, how _____

Emotional status

1. Did/do you notice any mood disorders in your partner's behavior after his prostate cancer treatment?

No Anxiety Negative affect Depression Other

Please specify: _____

If so, did/does it affect his sexual status?

Yes No Sometimes

If Yes, to what extent?

Very high High Moderate Low Very low or none at all

Relationship

1. How important was the sexual relationship in the overall personal relationship with your partner before your partner's prostate cancer treatment?

Not important Somewhat important Very Important

2. How important is the sexual relationship in the overall personal relationship with your partner after his prostate cancer treatment?

Not important Somewhat important Very Important

3. How would you rate your overall sexual relationship with your partner?

Poor Satisfactory Good Very good Excellent

4. How would you describe your partner's attitude toward the sexual relationship?

Poor Satisfactory Good Very good Excellent

5. How have the non-sexual components of the relationship (e.g. bonding, quality time, snuggling) changed since your partner's treatment?

More The same Less

Please give examples _____

6. Has your relationship with your partner changed since prostate cancer treatment?

Yes No

If Yes, please explain how _____

7. What advice would you give to other couples? _____

Self image

1. How has the sense of your partner's male self-esteem changed since his prostate cancer treatment?

Increased Remained the same Decreased

2. How would you describe your sense of his physical appearance since his treatment?

Satisfied Unchanged Unsatisfied

3. How would you describe his sense of his own physical appearance since prostate cancer treatment?

Satisfied Unchanged Unsatisfied

4. How would you describe your overall attitude regarding your sexual function since your partner's prostate cancer treatment?

Completely satisfied

Mostly satisfied

Fair

Mostly unsatisfied

Completely unsatisfied

5. How would you describe your overall attitude regarding his sexual function since his prostate cancer treatment?

Completely satisfied

Mostly satisfied

- Fair
- Mostly unsatisfied
- Completely unsatisfied

6. How do you feel your partner's self image changed since his treatment? _____

Partnership quality

1. Do you have a good partnership? Yes No
2. Is your relationship with your partner very stable? Yes No
3. Is your partnership strong? Yes No
4. Does your relationship with your partner make you happy? Yes No
5. Do you really feel like part of a team with your partner? Yes No
6. Could you please rate the degree of your happiness in your partnership:
-10 _____ 0 _____ 10
very unhappy neutral perfectly happy
7. How often have you and your partner seriously discussed ending your relationship?
Never Once-Twice More often
8. Do changes in sexual function of your partner affect your serious consideration to end your relationship with him?
Yes Somewhat No Not applicable
If Yes or Somewhat, please explain

Support

1. How did you support your partner after his cancer treatment? _____
2. Did your support help him to improve his sexual activity?
Yes No
If Yes, did it also help yourself as well as his self confidence after his cancer treatment?
Yes Somewhat No
3. Were any other particular coping mechanisms helpful?
support groups psychological support other

Concluding questions

1. Are you ultimately pleased with your partner's prostate cancer treatment choice?
Yes No
If Yes, please specify _____
2. Do you feel that the side effects (change in erection or sexual function, loss of urine, etc.) from his prostate cancer treatment were what you expected?
Yes No
Please explain: _____
3. Would you want to choose with your partner the same treatment for prostate cancer if it were done again (please explain) _____
4. What would you like to have known before treatment that you know now?

5. What advice would you give to other patients considering this form of prostate cancer treatment? _____