The Effects of Prostate Cancer Treatment on the Sexual Behavior of Gay and Bisexual Men: Key Results from the Restore Study

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Prostate Cancer (PCa) is the most prevalent cancer in men

PCa is most common cancer in GBM & Male Couples, yet remains understudied

- 17% prevalence = 125-175,000 GBM
  - 1 in 6 GBM

- 34% of male couples = 50,000 – 120,000 male couples
  - 1 in 3 couples

PCa onsets in mid/later-life

- 0.0% for <20
- 0.0% for 20-34
- 0.6% for 35-44
- 9.5% for 45-54
- 32.9% for 55-64
- 37.6% for 65-74
- 15.5% for 75-84
- 3.8% for >84

SEER 18 2009-2013, All Races, Males
PCa has high survival

5-year Relative Survival

Year

SEER 9 Incidence & U.S. Mortality 1975-2013, All Races, Males. Rates are Age-Adjusted.

University of Minnesota
PCa tx has side effects in heterosexual men

- 2, 5, & 15-years after PCa treatment:
  - All with Sexual Dysfunction
  - Urinary & Bowel Dysfunction
    - Sexual & Urinary Higher; Bowel, Lower for surgery tx vs. radiation
Significance of “Restore” study

Institute of Medicine (2012), in reviewing NIH concluded:

• the lack of research into GBM contribute to on-going health disparities experienced by LGBT
• used prostate cancer in GBM as a example of severe lack of research
• Restore is only the second study of prostate cancer in GBM that NIH has funded, and the first to have results reach publication.

Why is Prostate Cancer in Gay and Bisexual Men (GBM) important?

- Most common cancer affecting GBM: 1-in-6 GBM and 1-in-3 male couples will be diagnosed.
- Sexual outcomes of treatment are likely different for GBM than heterosexual men.*
- Because anal sex and vaginal sex are different physiologically, we cannot generalize so need to study GBM separately.
- Recruitment of GBM with prostate cancer into studies has been a major challenge. We need methods research to test recruitment methods.
- **Innovation**: Almost no research has examined the effects of treatment on GBM’s sexual behavior. (Only 1-2 pubs per year in English).*

“Restore” Study Methods

R21 mixed methods exploratory study

- **Aim 1: Qualitative**
- **Aim 2: Measurement development**
- **Aim 3: Quantitative survey of sexual behavior, needs assessment**

- *Primary Recruitment Strategy:* emails from Malecare, an online support group for GBM with prostate cancer

- **When:** 2015-2016

- **Aim 1:** one-on-one, semi-structured, in-depth qualitative interviews.
- **Aim 3:** Quantitative online survey.
AIM 1: QUALITATIVE KEY RESULTS
**ADVANCING METHODS: Q1**: In studies of older GBM who have had radical prostatectomy, is it better to use online or phone to recruit?

- GBM are a hidden population of early technology adopters where online methods to recruit are almost always better.
- Older people are the cohort least online where offline methods to recruit are almost always better.

So, to recruit older GBM, which is better – online or offline?

<table>
<thead>
<tr>
<th>What GBM chose:</th>
<th>Online</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>To be screened</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td>To be interviewed</td>
<td>1</td>
<td>17</td>
</tr>
</tbody>
</table>

**Answer**: Both – a mixed methods approach works best.

Q2. What are the effects of radical prostatectomy on GBM’s sexual behavior?

GBM report 3 pervasive sexual changes. Clinicians typically only address one (behavior), or worse, only discuss this as an issue for insertive, penetrative sex with their patients. This profoundly fails to address the realities of their patient’s experience.

Q2. What are the effects of radical prostatectomy on GBM’s sexual behavior? \([N=19\text{ GBM w surgery; in-depth interviews}]\)

1. Anatomical changes
   - Changes in penis size and shape:
     - “It’s like I had a penis transplant. That was the hardest thing…the cancer was easy!” [MSU06]
     - “The biggest surprise for me was how my penis was unrecognizable. It did not look the same. They don’t tell you that … it scared the daylights out of me. [MSU04]
   - Loss of ejaculate:
     - “Part of that change is loss. I can't tell you how much I miss cum. I miss it. I use a coconut shampoo because it feels and looks like cum. I love to touch that stuff. Those things are losses. When you have a loss, you really have to grieve, you have to mourn something that you love that you don't have anymore.” [MSU19]
   - Urination in sex:
     - “As a matter of fact, I don't take my clothes off because I'm embarrassed and humiliated. I have what they call arousal impotence. That's part of the reason my husband and I no longer have sex. He's not into that, and I don't blame him … it's disgusting … it's urine.” [MSU05]

Q2. What are the effects of radical prostatectomy on GBM’s sexual behavior?  
[N=19 GBM w surgery; in-depth interviews]

2. Participants report changes to all sexual behavior, not just insertive sex.

Changes to masturbation
- “When I'm masturbating, I would like it if the sensations were a little more like they were before. I don't think that's going to happen. It's just forever changed.” [MSU07]

Changes to oral sex
- “Oral sex is very important, and when you're pumping out urine, it's like oh, dear God. This isn't going to work. To have that? That was a huge hurdle.” [MDL0251]
- “I absolutely had anxiety and feelings and worries and concerns about losing my ejaculate. I still sort of mourn that I don't have it, but then that's something for you to appreciate about the man you're with.” [MSU08]

Changes to vaginal sex
- “My wife and I no longer have sex, because I'm not sure that I can get enough of an erection for penetration. We do other things but we, I mean, vaginal sex we don't do. I haven't been with a guy since [either].”

Q2. What are the effects of radical prostatectomy on GBM’s sexual behavior? \(N=19\) GBM w surgery; in-depth interviews

3. Treatment affects all phases of the sexual response cycle, not just excitement/erections.

- **Sexual Desire Phase:** “My libido is much less that it was before [the surgery].” [MSU13]
- **Excitement phase:** “It's not like it was…with an implant, there's almost no foreplay. It's soft one minute and rock hard the next minute, and it's very mechanical.” [MSU05]
- **Plateau:** “Watching porn is helpful … to get you excited. It’s difficult to prolong sexual excitement and to keep it going. If I lose the erection, it’s hard to get it back.” [MSU02]
- **Orgasm:** “For me, actually, I have to say my sex life is better. The orgasms are way more intense than they ever were before, much more longer lasting.” [MSU03]
- “The orgasms I have now are like when I was a pubescent. I feel it in the rear, right hand side of my brain.” [MSU06]

Q2. What are the effects of radical prostatectomy on GBM’s sexual behavior? \(N=19\) GBM w surgery; in-depth interviews

**Key Clinical Finding #1:**

If warned (e.g., about ED or loss of ejaculate), patients adjust well.

If not warned (e.g., about changes in penile size, shape, or climacturia), patients respond with anger and lasting resentment.

*Ethically, it appears we could do better warning GBM patients about common effects.*

Q2. What are the effects of radical prostatectomy on GBM’s sexual behavior? \([N=19 \text{ GBM w surgery; in-depth interviews}]\)

**Key Clinical Finding #2:**

GBM have common questions that they do not ask physicians that may affect recovery.

- How long after surgery should I wait before anal stimulation?
- Can I tear anything? Can I use an enema?
- How long should we wait for receptive anal sex?
- If I’ve had brachytherapy can that push the seeds into my partner’s urethra?
- Partners: Can I get PCa from the patient?

Q3. What are the effects of radical prostatectomy on GBM’s emotional health? [N=19 GBM w surgery; in-depth interviews]

5 emotional themes:
1. Shock (at the diagnosis)
2. A reactive depression
3. Sex-specific situational anxiety
4. Grief
5. Loss of sexual confidence/esteem

Emotionally, it can leave the patient feeling old and useless.

“I feel less than the average gay person.” [MSU17]

“I'm still kind of getting out of this, but for a long time I felt like I was severely damaged. Therefore, completely undesirable. I withdrew.” [MSU09]

Q3. What are the effects of radical prostatectomy on GBM’s identity? \( N=19 \) GBM w surgery; in-depth interviews

How does treatment affect identity?

1. No change in sense of being gay or bisexual
2. Decrease in sense of maleness/being a man
   - “When you have this ... it can be so devastating and your identity has got to be bigger than your penis. ... If you’re bisexual, if you’re gay, [the] penis is more and more and more important. I just think it’s almost a matter of forcing people to re-identify themselves which is a really hard thing to do.” [MSU09]
3. Some men change their role-in-sex identity as “tops” to “bottoms”; other men can’t.
   - “I’ve gotten to this point where I hate it when people say, ‘Well, you know, as a gay man, you have an option. You can always bottom.’ It isn’t that simple. You can’t just change your sexual focus like that. ... I don’t think I could suddenly become a bottom any more than I could suddenly decide to go out and fly a 747.” [MSU01]

How does sexual health affect emotional health and relationships?

Figure 2. Visual Schematic of the Psychosexual Effects of Radical Prostatectomy on Gay and Bisexual Men

(N = 19 indepth qualitative interviews)

Sexual Challenges
1. Immediate post-surgery
2. Short & Longer Term
3. Long-term Effects

Behavioral Challenges
- Masturbation without erection
- Oral sex
- Vaginal sex
- Insertive anal sex
- Receptive anal sex

Anatomical Changes & Challenges
- Penis characteristics (i.e., size, color, shape)
- Loss of ejaculate
- Erectile dysfunction
- Urinary trouble (i.e., leaking, climacturia)

Changes across Sexual Response Cycle
- Decreased sexual desire
- Changes in the excitement phase
- Plateau: inability to regain erection
- More intense orgasm

Identity Changes
- Role in sex identity (i.e. as top, versatile, bottom)
- Diminished masculinity & being a man
- Diminished sense of being a gay man

Emotional Challenges
- Shock at diagnosis
- Depression
- Sex-specific situational anxiety
- Loss of spontaneity
- Loss of sexual confidence

Disclosure Challenges
- Disclosing to potential partners
- Dealing with negative reactions from new and former partners

Relationship Challenges
- Partner reaction
- Addressing discrepancy in sex interest
- Addressing anatomical changes
- Addressing roles in sex in the relationship
- Renegotiating sexual exclusivity
Q4. What can we learn from these men’s experience? Innovative strategies GBM use to manage the sexual effects of radical prostatectomy?

1. Take selfies of your penis flaccid and erect *before your* surgery to help with remembering and rehabilitation *after*.
2. Video yourself ejaculating so you can remember celebrate, and enjoy.
3. Cock rings help with erections
4. Vacuum pump helps to restore size
5. Pelvic floor exercises (in addition to Kegels) can help with urine control.
6. Involve your male partner(s) in rehabilitation – its affects them
7. Start Cialis and Kegels at least a week before surgery
8. Before rushing into surgery, take sufficient time to lose weight, get fit, and give up caffeine (diuretics) to improve surgery outcomes.
10. Have your partner ejaculate first and then use his ejaculate as lube, to give the feel and smell of ejaculate.
11. Learn other ways to be intimate with people that are not penis dependent. .. like massage exploring erogenous zone like nipples or scrotum.
12. Send your partner to get a Cialis prescription as well to have enough.
13. You need to be your own cheerleaders and fight for sex.
Q5. What are the effects of radical prostatectomy on GBM-physician relationship [N=30 GBM prostate cancer survivors; in-depth interviews]

GBM engage in 4 strategies re sexual orientation disclosure to specialists:

1. Explicitly out themselves as “gay or bisexual”:
   • “I wouldn’t do business with any doctor unless they know I am gay. … I talk about how much of a slut I am … the whole spiel. I don’t hide.” [MRT06]

2. Evaluate the specialist to decide whether to disclose:
   • “A lot of [gay men with prostate cancer] live where they can't be open about being gay and can't ask their doctor about it ... That's a lot different than at [a university-based hospital]. I assume that every doctor in the university has [had] human sexuality education and has a certain ability to deal with the shit.” [MSU07].

3. Assume the specialist already knows or can infer (e.g., from demographics)
   • “We never talked about it. … I figured he kind of knew.” [MSU12]

4. Elect not to disclose
   • “[‘My gay life’] has never come up, but I'm sure [the] doctors know, I know [my doctor’s] very Christian. That keeps me from opening up to him about that.” [MOT04]

Q5. What are the effects of radical prostatectomy on GBM-physician relationship [N=30 GBM prostate cancer survivors; in-depth interviews]

How physicians handles sexual orientation disclosure affects patient outcomes.

When physicians treat orientation disclosure sensitively -> ↑Trust

- “I had identified myself as gay before the appointment. He knew that. At one point in the appointment, he invited my wife to leave the room. … We talked openly and honestly at that point.” [MRT03]

When physicians discount or appear uncomfortable -> Patient terminates.

- “He [the urologist] said, “Bring the wife in, and we can discuss it.” I’d already told him several times I was gay. I went back to my GP, and he said, “Go, do radiation.”” [MRT02]
- “The urologist, who I went to for the biopsy, when I identified myself as a gay man, he immediately walked behind the desk and sat down and never came close to me again. … He really wanted nothing more to do with me or I with him, so I left that practice immediately, that's in my local hospital, and I went to [a large University-based hospital]” [MRT03].

Q6. What types of social support do GBM receive [N=30 GBM prostate cancer survivors; in-depth interviews]

• Existing social support frameworks:
  – Instrumental: hands-on, caregiving
  – Emotional: emotional, mental support
  – Informational: practical information (referral to doctor)
  – Appraisal: helping make informed decision

• By treatment type
• By timeline of treatment

Q6. What types of social support do GBM receive? 
\( N=30 \) GBM prostate cancer survivors; in-depth interviews

<table>
<thead>
<tr>
<th>Treatment Timeline</th>
<th>Support</th>
<th>Network</th>
</tr>
</thead>
<tbody>
<tr>
<td>Through (out)</td>
<td>Instrumental, Emotional</td>
<td>Partners, Friends, Family, Support Groups</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Friends and partners attended doctor's appointments; emotional support throughout</td>
</tr>
</tbody>
</table>

Q6. What types of social support do GBM want more?

[\textit{N}=30 GBM prostate cancer survivors; in-depth interviews]

### Social Support Wanted More / Tasks Done Alone

<table>
<thead>
<tr>
<th>Treatment Timeline</th>
<th>Support</th>
<th>Network</th>
</tr>
</thead>
<tbody>
<tr>
<td>Throughout</td>
<td>Informational / Emotional / Appraisal</td>
<td>GBMPCa Support Groups</td>
</tr>
<tr>
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</tbody>
</table>

Aim 3: Quantitative Survey Results
### Figure 1. Recruitment Flow Diagram Showing Participation Rates in the *Restore* study

<table>
<thead>
<tr>
<th>Wave:</th>
<th>All Email/ Social 10 days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strategy:</td>
<td>502</td>
</tr>
<tr>
<td>Days:</td>
<td>434</td>
</tr>
<tr>
<td>Click Throughs:</td>
<td>417 (96.1%)</td>
</tr>
<tr>
<td>Passed Eligibility:</td>
<td>233 (55.9%)</td>
</tr>
<tr>
<td>Consented:</td>
<td>194 (46.5%)</td>
</tr>
<tr>
<td>Rejected as Spam:</td>
<td>193 (100%)</td>
</tr>
</tbody>
</table>

In your typical online study (where no one meets the subjects), how important is it to have a de-duplication and cross-validation protocol?

Figure 1a. Recruitment Flow Diagram showing Spam by Time and Where Recruited

Wave: Wave 1
- Email 1
- Social media
- Strategy: Days: 7 days
- Click Throughs: 88
- Passed eligibility: 64
- Consented: 59 (92.1%)
- Rejected as Spam: 0 (0.0%)
- Valid & Unique: 59 (100%)
- Completed survey: 58 (98.3%)

Wave 2
- Social media
- 15 days
- 204
- 175
- 168 (96.0%)
- 145 (86.3%)
- 59 (100%)
- 23 (13.6%)
- 48 (72.7%)
- 23 (100%)
- 48 (100%)

Wave 3
- Email 2
- 9 days
- 73
- 68
- 66 (97.1%)
- 18 (27.2%)
- 48 (72.7%)
- 23 (100%)
- 48 (100%)

Wave 4
- Email 3
- 27 days
- 111
- 103
- 101 (98.1%)
- 60 (59.4%)
- 51 (50.0%)
- 13 (59.1%)
- 13 (100%)

Wave 5
- Email 4
- 18 days
- 26
- 24
- 23 (95.8%)
- 60 (59.4%)
- 51 (50.0%)
- 13 (59.1%)
- 13 (100%)

All Email & Social Media
- 502
- 434
- 417 (96.1%)
- 233 (55.9%)
- 10 (43.5%)
- 60 (59.4%)
- 18 (27.2%)
- 194 (46.5%)
- 193 (100%)

Demographics
[N= 193 Gay and bisexual men treated for prostate cancer]

- Residence: USA: 95%; Canada: 5%
- Race/Ethnicity: White/European (89%); Black (5%); Latino (3%)
- Sex Orientation: Gay (91%); bisexual (9%)
- HIV Status: HIV-negative (87%); HIV-unsure (1%); HIV+ before treatment (11%); HIV+ since treatment (2%)
- Years since Treatment: 6.7 yrs (SD=3.6; Range: 7 months-12 years)
- Treatment:
  - Prostatectomy: 51%
  - External radiation and/or brachytherapy: 18%
  - Systemic (surgery and external radiation w or w/out medical castration): 28.0%
  - Diet and/or alternative therapy (e.g., selenium, vitamin E): 2%
  - Watchful surveillance: 1%

Geography of Residence

Geographically dispersed sample (+ Alaska and Hawaii).
Key Results
[N= 193 Gay and bisexual men treated for prostate cancer]

✓ Hypothesis 1: Erectile difficulties will be common, severe, and negatively correlated with quality of life.

Last 4 weeks:
• Common: 78% described their erections as less than good.
• Severe: 85% said quality of erection less than firm enough for intercourse

• Quality of life (EPIC):
  – Sample has significantly worse urinary function, and hormonal function and bother, but better sexual function and bother than published (heterosexual) norms.

Key Results
[N= 193 Gay and bisexual men treated for prostate cancer]

Incidence of Sexual Activity

- How many GBM are sexually active, post treatment for prostate cancer surgery?

At least once:

- Felt sexual desire: 91%
- Masturbated: 87%
- Oral sex: Insertive 42%; Receptive: 55%
- Vaginal sex: 6%
- Anal sex: Insertive: 25%; Receptive: 37%

91% reported at least one sexual behavior

Clinical implication: Assume your pt’s are sexual, post treatment.

Key Results
[N= 193 Gay and bisexual men treated for prostate cancer]

✓ **Hypothesis 2: Erectile difficulties will be pervasive across behavior.**

- Erections good enough for insertive anal sex (24 of 107): 22%
- Erections good enough for vaginal sex (4 of 19): 22%
- Getting erections: 86% reported some problems getting erections and 54% always having problems
- Reaching orgasm: 85% report at least one recent incident of difficulty reaching orgasm in insertive anal sex.

Key Results
[N= 193 Gay and bisexual men treated for prostate cancer]

✓ **Hypothesis 3: Condom use by GBM treated for prostate cancer will be low.**

*Insertive anal sex, last 3 months:*
  - Not using condoms with any partner: 87%
  - Not using condoms with one partner: 4%
  - Not using condoms with two partners: 4%

*Receptive anal sex, last 3 months:*
  - No unprotected sex: 79%
  - Unprotected with one partner: 13%
  - Unprotected with 2 partners: 4%
  - Unprotected with >2 (Range: 4-20): 2%

Condom use appears very low for insertive but not receptive sex. 61% of GBM who engage in insertive anal sex reported erection concerns as a reason to not use a condom.

Of concern, 3 men had become HIV+ since undergoing prostate cancer treatment.

Key Results
[N= 193 Gay and bisexual men treated for prostate cancer]

✓ **Hypothesis 4:** For men who engage in receptive anal sex, anodyspareunia and anorgasmia will be common.

Men who engage in receptive anal sex (N=92)
- Sexual functioning as poor or fair: 35%
- Dissatisfied with quality of receptive sex: 27%

**Incidence (last 4 weeks):**
- Recent pain in receptive anal sex: 57%
- Anodyspareunia: 34%
- Bleeding or irritation: 30%

Currently 37% report receptive sex as painful to having no feeling compared with 14% in the year prior to treatment.

Hypothesis 5: Structured rehabilitation, out as being gay/bisexual; out as having prostate cancer, out to your specialist, and internalized homonegativity will moderate sexual recovery.
Interpreting the Main Findings
[N= 193 Gay and bisexual men treated for prostate cancer]

Main finding #1:  
Against the stereotype of older men being no longer sexual, almost all the sample reported recent sexual behavior

Main finding #2:  
Most rate the quality of their sexual functioning as highly problematic.

Conclusion: Sexual recovery after treatment is possible but very challenging.

### Sexual Rehabilitation Treatment – What are doctors doing about it?

[N= 193 Gay and bisexual men treated for prostate cancer]

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Sort of / maybe</th>
<th>No</th>
<th>Don’t remember</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did anyone discuss with you the sexual effects of treatments (e.g. erectile difficulties, loss of semen)</td>
<td>56.5%</td>
<td>25.9%</td>
<td>15.5%</td>
<td>2.1%</td>
</tr>
<tr>
<td>As part of your prostate cancer treatment, did anyone take your sexual history</td>
<td>8.8%</td>
<td>17.6%</td>
<td>69.4%</td>
<td>4.1%</td>
</tr>
</tbody>
</table>

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Is anyone discussing the common effects of their treatment with patients? [N= 193 Gay and bisexual men treated for prostate cancer]

<table>
<thead>
<tr>
<th>Effect</th>
<th>Experienced</th>
<th>Discussed prior to Tx</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of ejaculate</td>
<td>94%</td>
<td>71%</td>
</tr>
<tr>
<td>Erectile difficulties</td>
<td>90%</td>
<td>74%</td>
</tr>
<tr>
<td>Change in sense of orgasm</td>
<td>87%</td>
<td>24%</td>
</tr>
<tr>
<td>Loss of sexual confidence</td>
<td>77%</td>
<td>10%</td>
</tr>
<tr>
<td>Changes to the penis</td>
<td>66%</td>
<td>23%</td>
</tr>
<tr>
<td>Increased pain in receptive anal sex</td>
<td>65%</td>
<td>4%</td>
</tr>
<tr>
<td>Urinary problems not related to sex</td>
<td>64%</td>
<td>75%</td>
</tr>
<tr>
<td>Urinary problems during sex or at orgasm</td>
<td>49%</td>
<td>30%</td>
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</table>

Only 3 of the 8 most common problems, experienced by most participants, were discussed prior to treatment.

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What do GBM treated for prostate cancer want? [N= 193 Gay and bisexual men treated for prostate cancer]

We conducted an extensive needs assessment. Key results:

- Interest in sexual recovery program? 98%
- Preferred format, online: 72%
- Language: formal or street, not indirect
- Content: stories of other GBM very high
- Topics: #1 sexual effects of tx
  #2 mental health effects
  #3 how to have sex with men, post
  #4-5 education on prostate and PCa
- Exercises: sex and urinary ex.s important

Only Minor differences by race/ethnicity and treatment type observed

<table>
<thead>
<tr>
<th>Interest in Sexual Rehab Program</th>
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<tbody>
<tr>
<td>Not at all interested</td>
<td>2%</td>
</tr>
<tr>
<td>A little interested</td>
<td>11%</td>
</tr>
<tr>
<td>Somewhat interested</td>
<td>19%</td>
</tr>
<tr>
<td>Very interested</td>
<td>32%</td>
</tr>
<tr>
<td>Totally interested</td>
<td>35%</td>
</tr>
</tbody>
</table>

Informational and Emotional Support Most Common Types of Support Received
More support from chosen family and friends than biological family
Men wanted more support from GBM Support groups and Emotional Support
Low/Wanting More Social Support Associated with Lower HRQOL (☆ = statistically significant)

<table>
<thead>
<tr>
<th></th>
<th>PCA - Hormonal</th>
<th>PCa - Sexual</th>
<th>PCa - Bowel</th>
<th>PCa-Urinary</th>
<th>General - Physical QOL</th>
<th>General - Mental QOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low General Support</td>
<td>☆</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td># of Types of PCa Support</td>
<td>☆</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td># of Providers of PCa Support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td># of More Social Support Types Wanted</td>
<td></td>
<td></td>
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</tbody>
</table>

- Low General Support: Low General Support is statistically significantly associated with Lower HRQOL.
- # of Types of PCa Support: A high number of types of PCa support is associated with Lower HRQOL.
- # of Providers of PCa Support: The number of providers of PCa support is not statistically significantly associated with Lower HRQOL.
- # of More Social Support Types Wanted: A high number of more social support types wanted is associated with Lower HRQOL.
Social support implications - Need new measures, interventions

- Need better measures of support networks/types specific to cancer that include non-biological family
- Dyadic observational & intervention studies
- Social support groups and translational research to support interventions
- What are relevant social support types and networks needed throughout later life?
  - Especially re: short-term and long-term support needs?
Research Considerations
Limitations

• Self report surveys only by patients not providers
• Convenience sample not randomly chosen
• Relatively small sample size
• Area of study not well-researched so reliability and generalizability not well known.
• Recruitment from a support site may bias results
Strengths

• Largest qualitative study of GBM ($N=40$ in depth interviews) with prostate cancer ever conducted – good saturation and allows for finer comparisons by treatment type

• Largest quantitative study of GBM treated for prostate cancer ever conducted ($N=193$)
  – Shows potential for recruiting online
  – Advances our understanding of sexual behavior post-treatment
  – Comprehensive look at sexual behavior

• First needs assessment of GBM treated for prostate cancer
  – Gives us data on acceptability for rehabilitation options
Implications for Practice

• GBM with prostate cancer has distinct needs that are different from heterosexual men
• Sexual and urinary rehabilitation is possible but it’s very challenging and needs focus
• GBM patients have distinct questions that deserve answers
• Compared to heterosexual men with PCa, GBM has less social support and are more isolated
• Sexual rehabilitation of GBM with prostate cancer
  – We have submitted an NIH application to develop and test an online sexual rehabilitation curriculum tailored to GBM prostate cancer survivors.

• Needs of partners/spouses during prostate cancer treatment
  – We have submitted an NIH application to conduct larger mixed-methods (qualitative/quantitative) research to understand needs of partners throughout treatment and sexual rehabilitation.

• Comparative study of GBM vs heterosexual men studying outcomes

• Development and evaluation of a training module for urology residents to develop competency in treating GBM with prostate cancer.
Research Opportunity

• If you are a GBM with prostate cancer, please we are seeking volunteers to advise our work.

• Please email Simon at: Rosser@umn.edu

• (or see us after)
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Thank you and wishing you good sexual health!

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