Individual and Couple Side-Effects after Radical Prostatectomy (RP): Personal Reflections from a Research Scientist and Other RP Patients

Author

Walter R. Schumm[1]

Affiliation

[1] College of Health and Human Sciences, Kansas State University, Manhattan, KS 66506-1403

United States of America

Contact Information:

Walter R. Schumm, Ph.D.

College of Health and Human Sciences, Kansas State University,5900 Lake Elbo Road, Manhattan, KS 66502-8996 USA

Tel: 1-785-539-3641 or 1-785-564-1604;

Fax: 1-785-532-5505

E-mail: schumm@ksu.edu or schumm@k-state.edu or wrschumm@aol.com

Keywords: radical prostatectomy, prostate cancer, cancer, urological oncology, sexual side-effects, couple/family systemic effects, qualitative methods

Abstract

Objectives: To provide medical staff who provide support to prostate cancer patients more detailed information on how side effects are experienced by those patients as well as the limitations of generally recommended treatments from the perspective of a patient who is also a research scholar. As the author experienced side-effects and discussed them with other RP patients, it became apparent that side-effects and their treatments were more complex than he had been informed prior to his treatment. Some medical staff may not know as much as they should about such details, limiting their ability to help patients in their recovery from radical prostatectomy.

Methods: As a qualitative study, throughout four years after experiencing radical prostatectomy, the author kept notes on his experiences, and those of several acquaintances who had the same surgery about the same time, with bowel, urinary, and sexual side effects of the procedure, how those effects changed over time, and varying results obtained from recommended treatments. At the same time, the method was enhanced by a review of numerous books and scientific articles for related material on side-effects and their treatment that were relevant to the patients' experiences. Although an unusual methodology, it allows for more detailed assessment of possible side-effects for patients and medical support staff to consider than other, strictly quantitative, approaches.

Results: There are some positive outcomes from radical prostatectomy other than the cure of cancer; however, negative side-effects may be more prevalent. Most of the patients here reported disappointment, regardless of their source of treatment, because of their limited success in managing at least some of the side effects, especially sexual side-effects. Some of the recommended treatments require greater knowledge for successful implementation than often provided by medical staff. Overcoming side-effects often requires support from the cancer patient's partner or family and may not be achievable without that support. Several scales to measure aspects of these issues were developed but remain to be tested for reliability and validity.

Conclusions: Patients need more detailed information on side-effects prior to selecting a treatment method so they can make more informed choices for their own treatments. More detailed information is needed on how to implement treatments for side-effects as well as involvement of their partners and family in dealing with side-effects, especially sexual side-effects. In terms of future research, there is a need for improved measurement of the side-effects of cancer treatment as well as potential family support during/after treatment.

1 Introduction

Prostate cancer (PCa) is one of the most common forms of cancer in men in both the developed world and elsewhere[1]. It may be the most common non-skin cancer in America[2] and is reported to be the most frequent cancer among males in Europe[3]. Almost 20% of new cancer diagnoses in men will be for prostate cancer[1]. While, it has one of the highest survival rates of any cancer[2], it is the fifth leading cause of cancer death among men[4]. It has been estimated that nearly 32,000 men in the United States would die from prostate cancer in 2019[1]. While there are several possible approaches to treating prostate cancer, perhaps the most common is radical prostatectomy (RP), which involves surgical removal of the prostate and often the seminal vesicles or part of the neck of the bladder[2,5,6]. RP appears to be associated with increased survival rates relative to some other treatments[7,8]. Nguyen et al.[9] describe RP as the "most established curative treatment for localized prostate cancer" (p. 760).

However successful treatment of cancer may be, adverse side effects from RP can occur, including urinary incontinence, erectile dysfunction, bowel symptoms (1) and a sense of loss of masculinity[10,11], any of which can reduce quality of life significantly. Elsewhere, side effects with respect to urinary incontinence and bowel control have been discussed in more detail.[10] Here, the goal was to emphasize sexual side-effects, especially from a systems perspective in terms of how individual effects can lead into couple or family effects. Adverse side-effects can increase treatment (RP) regret[12]. Despite the focus of this report on adverse side-effects, it should not be forgotten that there are many positive effects of prostate surgery, including saving one's life, regaining nighttime control of urine flow, being able to urinate freely without obstruction or excessive delay, as well as many healthy behaviors that may be learned as a way of reducing the chances of future cancer events. A patient's risk/reward ratio could suddenly change if the patient were to realize that their case of cancer was not a life-at-risk issue, as that might magnify the negativity associated with adverse side-effects (i.e., I gave all this up and it wasn't to save my life?).

2 Methods: A Personal History Approach Cross-Checked with Similar Patients

The author had annual check-ups for prostate cancer, partly indicated by a relative having received a diagnosis of metastatic prostate cancer at age 62, leading to hormone therapy, which destroyed his libido, although he continues to survive at age 88. At age 64, my primary care physician thought he detected a nodule in the prostate, even though my PSA was only 2.6, below the limit of 3.0 recommended elsewhere[4]. One patient did not have detectable cancer at one annual physical examination, but after he skipped his next annual evaluation, it had metastasized by two years later, a pattern not fitting recommendations to test for prostate cancer only every two years[4]. One patient was castrated as part of his treatment, leading to inspection by multiple medical staff during each annual physical so the staff can say they have seen "a real eunuch."

When my primary physician referred me to a urologist, the urologist thought he detected a nodule as well, which led to a biopsy in March, which found a Gleason score of 9. However, at the time scheduled for the biopsy, no nodule could be detected, which led to a (mental) coin flip to determine whether to go ahead with the biopsy. After discussing several possible treatment approaches with the urologist, this author and his wife selected a national cancer treatment center (CTC) for follow-up

treatment, which began with a week of testing in April and RP surgery in June. Quarterly follow-ups followed for the first year, then semi-annual for two years, and now annual check-ups are scheduled. It is now over four years since the surgery.

I think it's reasonable to say that. when you have gone through an experience, including cancer treatment, you have a better sense of what that experience is like than if you haven't gone through it. One might even suggest that physicians might serve their patients better if they themselves had experienced their own treatments. This report brings not only a "patient's" perspective, but the perspective of a patient who has a several-decades-long experience conducting research in family and medical issues. Furthermore, I cross-checked my observations with those of several acquaintances who had prostate surgery, usually about the same time as myself, to minimize exclusive reliance upon personal but anecdotal evidence. My sense is that many RP patients and their partners have concerns and questions that they find difficult to articulate, so they don't share their concerns with their medical support team. Medical support teams may not want to risk offending RP patients or their sexual partners by asking them about any unexpressed concerns or questions. Here I hope to open up many of these silent topics for consideration. Thus, while different than more common approaches, it may be able to offer both clinical and research insights not as readily available through other, especially quantitative, methods.

3 Perspective

The author has been engaged in research in a variety of areas, including Gulf War illnesses and program evaluations, since the 1970's, with over 250 journal articles and several books published. Therefore, before, during, and after treatment for cancer, I was questioning if the assessment procedures were effective, were the treatments effective, and how were the side-effects being managed? What seemed to be missing in the treatment process? What could be done more effectively? Were informed consent procedures complete and accurate? Are cancer victims being offered treatments that are costly and not effective? I have a network of friends who also received RP locally or at other national CTCs, who have discussed the outcomes of their treatments with me. Thus, this report represents a patient perspective on sexual side effects of RP but from a patient used to research questions, procedures, and objectives, a perspective seldom reported in the medical literature. As a preliminary illustration, one patient brochure[13] discussed Walter, a patient at a CTC who had RP but was having difficulty having an erection eight weeks after surgery. His therapist was a young female social worker. Of the several men, I've talked to, none recovered full erectile capability until at least six months and some not at all for up to several years. A brochure that normalizes "cure" after merely a few weeks can adversely impact patients for whom side-effects are much longer lasting. My view would be that a patient brochure should discuss a wider range of outcomes and treatments rather than assuming unusually rapid "cures" to be typical.

4. Results

4.1 Bowel Issues.

Although I have discussed bowel issues elsewhere[10], I will briefly mention them here. While bowel issues might seem tangential to sexual side-effects, there can be connections. Without a prostate against which to push when expelling a bowel movement, pushing can be more difficult. At least in the initial stages of recovery, too much pushing could further damage tissue,

including the urethra, barely beginning to recover from surgery. Solutions in the short run include stool softeners, while increased and regular consumption of fiber will maintain regularity in the long run. Magnesium supplements may also help. Some foods may be need to be avoided altogether or eaten sparingly if they tend to lead to constipation. A non-supportive partner might mock the patient for having constipation issues more often or might criticize the avoidance of foods that may have romantic connotations – for example, if date nights usually involved ice cream, one's partner might disparage the patient for not being the same old romantic partner when ice cream is avoided or eaten only in minimal amounts. "What's wrong with you that you can't eat boatloads of ice cream like you used to eat" might not come across as supportive and conducive to later sexual activity. If the patient has had a couple of bad days and needs an enema for help, a partner might further mock the inability to handle one's bowels without "drastic" help. Given that most television advertisements regarding constipation seem to feature women, a patient might feel that some of his masculinity has been challenged – "I am becoming like those women in the TV ads, often in need of help with constipation, unlike most of my male peers who haven't had prostate cancer." Cancer treatment teams will need to consider the couple/dyadic side effects of cancer treatments, as suggested here.

4.2 Urinary Issues.

The urinary system is directly damaged in several ways from prostate surgery. Prior to surgery, the prostate probably served as one of three controlling valves, enabling most men to avoid bladder leakage problems well into old age. As with bowel issues, most television ads seem to target women with respect to needing further help with bladder leakage problems. Some friends of mine, accordingly, labeled themselves members of the "rusty zipper" club after prostate cancer surgery. At any rate, as with less bowel control, a cancer patient may feel that they have lost an important degree of control over bladder leakage, even though using only one pad a day has been reported as self-reported continence by patients[14]. It is possible that not only may that make them feel like less of a man (having not had any such problems before surgery), their partner may tease them about joining the club of women with respect to this issue. Furthermore, a partner may resent being the victim of the man's bladder leakage while trying to engage in sexual intercourse[15], a not infrequent problem, even without erectile dysfunction as an issue. Frey et al.[16] reviewed the literature on orgasm-associated incontinence (OAI) and urinary incontinence in relation to sexual stimulation (UISS) and found rates as high as 93% although average rates were lower in the range of 20-45%. Before surgery, there was a valve in the prostate that stopped urine flow when ejaculation was about to occur; without the prostate and that valve, bladder leakage during sex is possible. Wearing adult diapers may not strike one's partner as particularly sexy either; again most TV ads appear to feature women wearing bladder control materials, so the man wearing similar items may feel less manly, which won't help sexual confidence either.

When talking with our surgeon prior to surgery, I foolishly stated that I didn't want to spend the rest of my life wearing diapers, but now I realize that wearing diapers has many advantages. It virtually eliminates worry about wetting one's outer clothing and even controls for wet gas. There are issues seldom mentioned. Many surgeons remove part of the bladder when performing RP[17]. Researchers have found it difficult to predict how RP differentially affects

patients; incontinence may be a bigger problem that many surgeons are willing to admit, and rates of incontinence a year after RP may be as high as 50%[17]. Penson et al.[18] found that total urinary control declined from 87% before RP to 35% at five years after RP. First, wearing a catheter after surgery can bend the penis into an angle that directs the flow of urine toward the edge of the diaper rather than the center, so early on the man will need to arrange his penis in a more central position to best control leakage. Second, wearing a diaper while doing sweaty work can fill the material with sweat even if you aren't leaking, so their use on hot days may require more changes. Third, bladder control is an ongoing process that generally gets better over time. At first, a man may leak for virtually any reason, but as control improves, leakage may only occur under stress of some sort, whether physical or emotional. One last barrier to complete control may involve the ability to pass gas without leakage since you are releasing one set of muscles to pass gas while trying to contract closely related muscles to avoid leaking, a challenging behavior. Even then, lying down or sitting may improve control even when releasing gas. However, total control may never be achieved because one might experience more than one stressor at the same time; trying to carry a 50 pound box and sneezing while passing gas on a full bladder when one was very tired and overstressed might cause inadvertent bladder leakage even if none of the stressors by themselves would be a problem. A doctor told one patient that leaking was predictable when the bladder became nearly full and more frequent emptying was important; nonetheless, many patients recall that before surgery they never leaked no matter how full their bladder might have been. Another side-effect is that if a man (before RP) forgets to zip up when dressing, it becomes easy to detect when one encounters the outside weather (sense of cold or heat, wind), so the situation can be corrected; however, if one is wearing an adult diaper, the elements are less easily detected and one is more likely to fail to correct the situation before it is noticed by passersby, to one's embarrassment. One couple factor is whether the wife/partner will allow the patient to wear briefs that can contain a pad; if not, if the patient is only allowed by his partner to wear boxers, then the use of adult diapers may be the only solution, aside from devices that carry urine into various containers from the penis. Patients may not realize that some researchers define achievement of continence as needing only one pad a day for leakage[19] even after a year; in other words, if patients define continence as never having any leakage ever again no matter how severe the stress on their urinary system, they may be in for disappointment. Michi et al.[19] found that after a year, between 13 and 30 percent of patients needed two or more pads a day, while the rest may have needed at least one pad a day on occasion. Glickman et al.[14] found that over 23% of RP patients reported urinary control improvements between two and four years post-surgery. Mandel et al.[3] found that nearly half of RP patients with urinary incontinence at one year post-surgery recovered continence within two years afterwards. There are a variety of possible ways to reduce urinary incontinence[20,21]. However, it can be a concern when one finds more information on such treatments in a library or online than from one's medical support staff.

4.3 Sexual Issues.

While nerve sparing is standard procedure today, it is not always successful. For the sake of most of my arguments, I will assume that partial nerve sparing has been successful. In terms of organization, I will

discuss individual gains, losses, and solutions as well as couple gains, losses, and solutions. It appears that sexual side-effects are less likely for men under the age of sixty[22]. Despite any optimistic predictions that medical staff may give a patient, at least one source suggests that at least 50% of RP patients never recover, even in the long-term, an ability to have an erection[23]. There can be a loss of up to 70% of penile length and volume after RP[24]. At the same time, improvements in both urinary continence and erectile capability can occur between two and four years after surgery[14], where over 42% of RP patients reported improvements in erectile functioning between those times. Mandel et al.[3] found that among patients with ED at one-year post-RP, 36.5% recovered within the next two years. Sivarajan et al.[25] found some improvements, though mostly stable outcomes, out to 8/10 years for RP patients in terms of sexual functioning. Penson et al.[18] reported increases in adequate erectile firmness from 9% at six months to 28% at five years; however, age played an important role – 61% of men under the age of 55 reported adequate erections compared to 49% (55-59), 44% (60-64), and 18% (over 64). However, Frey et al.[16] found that many men lost orgasmic capability or experienced weaker orgasms with only 8% reporting stronger orgasms after RP. Furthermore, many men had pain with sex and experienced penile shortening (PS), although Frey et al. mentioned hyperthermia treatments as a potential treatment for PS. Adverse side-effects of RP can negatively influence male quality of life[24] and life expectancy[26].

4.3.1 Individual Sexual Issues.

There can be gains sexually from prostate surgery.

4.3.1.1 Sexual Gains.

First, a patient may learn how to have "dry" orgasms, which perhaps he could not experience when ejaculation was tied to orgasm so closely. Accordingly, he will have a gain in that he will be able, like women, to experience multiple orgasms or at least have a shorter refractory period between sexual encounters. Third, a patient may realize that sex is more mental than he ever thought, as before surgery he could focus on his ejaculation as a target goal without too much additional fantasy. In some ways, his sexual responsiveness will become more feminine which may help him understand a female partner's needs better, which could lead to better sexual interaction. Fourth, with some practice and freed from a focus on ejaculation per se, a man may be able to experience stronger, longer lasting orgasms that are no longer terminated by ejaculation. Fifth, while some orgasms may be "better", some may be weaker or shorter, with more variability (again, variability probably resembling that of a woman's sexual experience). However, the shift from a production mentality (ejaculation) that's also orgasmic to a purely orgasmic is more of a shift than one might imagine at first. The patient may be willing to undergo stimulation longer with orgasm as a goal whereas before surgery any failure to obtain ejaculation within a few minutes might lead him to quit earlier. As a whole man, he might find yourself walking around thinking about sex in terms of needing to empty your prostate as quickly as he can, maybe in a few hours; after surgery, he may find yourself walking around and thinking that it would be nice to have a good sexual encounter and orgasm sometime in the next few days. That is to say that his "horizon" for sex may change – and come to resemble more that of an average woman. If cleaning up semen is an issue for the patient, that issue will have been solved. Fewer studies

have examined orgasmic functioning after RP; Du et al.[27] found that ED was associated with reduced orgasmic functioning (OF) while younger age and greater nerve sparing was associated with greater OF. The patient may find that orgasms are possible without an erection but the feeling is akin to what might be called "a shadow orgasm", something happened perhaps but it might be hard to tell if it really did. Nevertheless, even partial erections are important, as the stronger the erection, the greater probability of having a better orgasm, perhaps where the greatest gain comes from having at least a 50% erection. However, with increased variability, even the best erection no longer guarantees a good orgasm as it might have before surgery.

4.3.1.2. Sexual Losses

There will be losses that may not occur for any or all men but may occur for some. The patient may lose the wonderful sense of feeling his semen starting to flow and the pleasure that comes as it exits his penis and starts it travels from there inside his partner's body, a feeling that the partner can miss as well (a couple effect). There can be a certain feeling of completion and relaxation that occurs with semen emission that is lost with RP[15]. He may lose the feeling that can come as his erection develops where the patient can almost feel the cells in his penis rapidly responding to his growing excitement; as far as the author is aware, that type of change has not yet been discussed in the research literature. He may lose the ability to have a strong erection that could no doubt penetrate as needed, leaving him with doubt as to whether his erection will be good enough for that experience. It's another way his manliness will be challenged since before surgery he probably was quite confident that he could rise to the occasion whenever and however, as needed. After RP, even if he is able to have an orgasm much of the time, it probably won't be 100% of the time. On paper that may not seem like much of a loss but the shift from 100% certainty to 80% or even less (= "maybe") is huge from a quality of life perspective. What if your paycheck only came in about 50% of the time? Would you *keep* that job? If your paycheck came in on time 100% of the time would you *leave* that job? One may realize how women might view sex differently if they only climax some of the time whereas their male partner(s) did it most or all of the time. For the "sometimes" sex partners, each try has orgasmic failure looming over it whereas for the always successful, there may not be even a miniscule thought of orgasmic failure. The mental differences are enormous, even if they haven't been described yet in research articles. RP may turn the patient from certain orgasmic success to "maybe" success, a huge emotional shift.

4.3.1.3 Before and After Surgery Issues.

It is a challenge to document all the qualitative differences that nerve damage can do. Before prostate surgery, the man and woman exchange body fluids but after, the man does not contribute to the woman. Before surgery, sex is a matter of urgency for the man, regardless of his emotional state, but after surgery, it is more of a nicety, less urgency. Before surgery, eagerness can describe a man's interest in sex; after surgery, far less. Both before and after surgery, a man and woman can enjoy each other's naked skin close up; however, the enjoyment of the thinner skin of the penis and vagina touching may be impossible if the man cannot sustain an adequate erection. Before surgery, the man can "deliver" so to speak; after surgery, not so. There is a pleasure in "delivering" on target whether it's a basketball into a basket, a football for a field goal, a soccer ball into the net, a letter

into a mailbox, a box into the post office, a pencil into its holder, a book into its place on the shelf, a casserole into its oven, dishes into a dishwasher. Men get used to a sense of accomplishment in which, even if they've had a terrible day at work, they can look forward to success at something, even if it's only delivering on target with respect to ejaculation. After surgery, that's lost permanently. One physician told a patient, in a matter of fact tone, "Well, you won't ever ejaculate again" – omitting the huge differences, as if they were unimportant, that can occur mentally and physically in so many areas of sexual interaction.

4.3.2 Couples Sexual Issues.

One of the glaring gaps in the research literature is lack of attention to couple issues regarding sexuality after prostate surgery[28]. As Wittman et al.[28] have noted "In usual busy clinical care, urologists treat ED; patients and partners' feelings about sexual losses and requisite adaptation of their sexual interactions go unaddressed". Wittman, with a small sample of 20 couples, found that if couples – both partners, despite any effects of aging - were willing to engage in intentional sex and to accept the use of sexual aids, their prospects were much better[28]. Carroll[5] reported that some physicians are beginning treatment for side effects earlier and more aggressively[20], but clearly other physicians tend to take more of a "wait and see" attitude about many side effects.

4.3.2.1 Couple Sexual Gains.

There can be couple gains. A man's need for a partner will be less to relieve physical tensions and semen buildup in his prostate and seminal vesicles, but will be more of an emotional or spiritual need, which may more closely mirror a wife's sexual needs. If a woman wants sex more often, a man may be able to engage in sex more often without having to worry about whether he's had enough semen buildup to make it possible. Conflict over sex may be reduced if before surgery, the man wanted sex far more often than his partner did, since not having prostate relief needs may reduce the urgency or felt need for sex. If a female partner doesn't want to become pregnant again, having a sterile male partner may be seen as an advantage, an opportunity to save money and time by no longer needing to use contraceptives. Another gain is that the man can now distinguish orgasm from ejaculation; before they were so closely tied together that orgasm might have been felt as a mere secondary accompaniment to the relief to the prostate provided by ejaculation. When trying to understand a woman's orgasm, a natural complexity was that it would be very difficult to understand her non-ejaculatory orgasm. In particular, a man might have heard that your best sex organ is your brain, but he probably senses that his best sex organ is his prostate, which demands relief on a regular basis. Only when that organ is "out of the way" does it become more readily apparent that the brain controls orgasm as much as anything else, which can help the man (finally) understand a woman's need for emotional support and encouragement for having the best orgasms. Another couple advantage may be if the woman didn't like having to deal with semen, that problem is now solved.

4.3.2.2 Couple Sexual Losses.

There can be couple losses. For starters, some medical staff tell their RP patients that up to forty percent of heterosexual couples never have sex again after the man's RP[10]. Such a stoppage of sex can occur with gay men as well after RP[29]. One study found that 85% of couples expressed dislike of erectile aids yet maintaining high expectations of success, presumably without them[28].

4.3.2.2.1 Fertility as a Loss.

If a husband or wife believed that the main purpose of sexuality is for the sake of having children, then sterile sex may seem pointless and no longer needed or desired. Even when is a wife is post menopausal, she may still believe that getting pregnant is a good, if very remote, possibility, so that having sex with her husband continues to retain meaning and purpose for that reason, a reason that is erased completely after prostate removal. Along a similar line of reasoning, once this author met a woman who believed that control over her body meant not only her right to an abortion but control over her male partner's fertility. That is, he should not be able to get a vasectomy or prostate surgery without her permission since his loss of fertility meant she was losing her right to become pregnant, if she wished to become pregnant. Such a woman might feel that prostate surgery was compromising not only her male partner's fertility but her own as well, thus damaging both her femininity as well as his masculinity. In both of these situations, the woman might feel betrayed by the medical profession if it was not made clear before surgery, that prostate surgery would make the man sterile for the rest of his life, and for the rest of their relationship they would be sterile as a couple.

4.3.2.2.2 Return of Previous Sexual Conflict.

If one partner fears that starting up a new sex life will bring back the same old sexual conflicts that existed before surgery, that partner may find ways to discourage, even sabotage, attempts to regain an active sex life as a couple. This might occur below a conscious level. If the surgery leads the husband to lose interest in sex, then the wife may feel less pressure to have sex when she's not interested and that may give her a greater sense of freedom. Once she feels that, she may feel why risk that new found freedom by going back to having sex?

4.3.2.2.3 Morality of Treatments for Sexual Side-Effects

It is becoming standard practice for men, after prostate surgery, to work at having erections, to preserve their penile tissues and their ability to expand upon demand. If a man were to do some of the needed things on a regular basis that might upset his wife, especially if she feels that masturbation is morally wrong or doesn't think that a penis needs regular expansion in order to maintain its shape, length, volume, and desired functioning. If the man does what is medically recommended, it may offend his wife's sense of morality and undermine the very reason he is going through his penile exercises.

4.3.2.2.4 Sexual Motivations

Before prostate surgery, a woman could probably have a regular sex life even if she depended entirely on her husband's interest to get things started. She might not even need to do much to stimulate him physically; the sight of her flirty nightgown might be all he needed to develop an erection. Similarly, she could count on him to be "ready" when she felt like it. The sexual relationship may be a 90/10 deal for some couples when it comes to who is responsible for sex occurring or at least attempts at initiating sex. That will likely change after prostate surgery. The man may not feel as much urgent need for sex, which may make her feel less desirable or less wanted, even if it seems to reduce conflict over frequency. Because of the many threats to a man's confidence in his sexual abilities, it may require that a partner take the initiative and become a cougar in a sense, assuming more responsibility for their sex life than perhaps was needed before surgery. If the partner is unwilling or unable

to do that, it may not bode well for a continued sex life. Both partners may need to realize that having sexual orgasms is a good thing for personal and emotional, health, even without anyone ejaculating. It may now have to be a 50/50 deal where the wife assumes as much responsibility as her husband for initiating and having sex.

4.3.2.2.5 Loss of Vicarious Sexual Pleasure.

In another way there may be a huge qualitative difference in that before surgery, at least one member of the couple was probably going to have some tension relief and an orgasm, even if the second person relied sometimes on a vicarious "it's better to give than to receive" motto when they failed to experience an orgasm. Now there is a serious chance that neither person will have a good time, which can serve as a serious de-motivator for having sex. In other words, before surgery, sex meant at least someone was going to have an orgasm; after surgery, it is more likely that neither person will, which both might now interpret as a "failure" at having sex. Before prostate surgery, for the cancer patient, sex may have been virtually a guaranteed good experience; it would take a lot of problems to make it otherwise. After surgery, it may become more nearly a guaranteed bad experience, where it would take a lot of things going right to make it otherwise. Such a shift represents a huge change emotionally.

4.3.2.2.6 Complexity of Preparations

If the man has erectile dysfunction issues after surgery, using artificial means to develop an erection may seem impersonal and take some preplanning and some time. If a wife, for example, challenges her husband with a comment like "Well, are you going to be able to get ready or NOT, tonight?" or "Are you going to try that cold penis on me again?" it may make him less likely to feel like getting ready. Or, if one partner were to say, "OK, you've got 20 minutes for this whole process, otherwise I'm going to sleep", then that may kill motivation, especially if past experience has shown that it might take 30 minutes If a woman insists that sex has to be spontaneous, without preplanning, then ED medications that require time to "kick in" may undermine her interest in sex since it may seem more preplanned to her than spontaneous. Even if the man achieves a viable erection, his partner may not perceive it as such and reject any overtures, saying "That's clearly not good enough" or "I don't want to risk things failing to work out" or "we might get started with that, but I doubt we'd be able to finish."

4.3.2.2.7 Feeling Less Needed.

One reason a woman may see meaning in participating in sex with a man is that she understands, at least at an intellectual level, that he has sexual tensions caused by his prostate needing relief and she may feel some obligation to help him with that. No matter what happens, she can tell herself that "at least I gave him some relief" and feel there was a concrete, tangible outcome for which she can take credit and gain some meaning for her life as well. To detail this a bit more, let's try look at things from a wife's perspective. Perhaps Mary likes to go to a local shopping area but the process takes at least a couple of hours and she likes to stop and take a break for some tea or coffee. The net result is that her bladder fills up. However, she doesn't like the restrooms in the shopping area and heads home, during which her bladder fills up even more. So by the time she gets home, she is desperate. However, she is wearing a dress that needs help when it comes to being unzipped. She asks her husband, who is busy with something else and doesn't really want to be bothered, to help her unzip. If he says "I'm

too busy" or "I have a headache" or "I'm just not interested" she would probably see that as a sign of not caring very much for her emotional and physical condition. However, he will probably help out regardless because the need is so apparent and he has similar needs, too. The bottom line is that her need becomes his need and his being needed makes him important as well and it's feels good to be important, it provides a sense of purpose and meaning in life. So even if he is not totally "into" unzipping dresses, he will probably do it and feel better for having done so. And the wife won't feel too guilty about asking him for help because his helping shows his importance as well and that importance makes him feel better.

However, that's the "before" situation. Let's suppose "Nancy" goes to her doctor for a cure for this problem and her doctor prescribes a pill that will cure bladder urgency and tells her where she can buy a dress or zipper puller that solves the zipper problem, so that she no longer needs her husband's help with zippers or bladder relief. That may be a great solution for her as an individual, but what will it do to their relationship? Now she never needs her husband's help. He doesn't get to feel needed or important any longer. He doesn't get to feel vicarious pleasure when she gets desperately needed bladder relief. He doesn't have the same bargaining power as in "OK, I will unzip your dress, but will you make me a coffee afterwards?" to which she will probably agree even if she really doesn't want to make him a coffee. What may look like a fantastic solution for the individual could have the effect of undermining the couple's relationship. That would be the "after" situation. The husband may be torn emotionally in three directions. While he may be glad to not "have to" help her with zippers, he may feel less needed and less important, thus feeling sad and useless. At the same time, it would be hard to argue with her "success" at solving her bladder and zipper issues for which he is no longer needed, especially since she is following "doctor's orders". He may wonder how impeccable medical treatment led him into this awkward condition where she doesn't seem to need him as much as before and he feels bad but doesn't seem to have much justification for feeling bad, especially as she has experienced a medical cure for her issues. "Nancy" may revel in her new found freedom from needing her husband in the same way but at the same time, she may wonder what will happen now to their relationship if he feels more unneeded, unwanted, and unimportant.

The analogy, of course, is that the prostate is functionally like a second bladder for the man. He didn't volunteer to have two bladders to worry about, but he's stuck with the situation. Even if his wife isn't really "into" sex and/or would rather do other things at any given time, she will probably do it out of a sense of his desperate need. Some have called this "mercy sex"[30]. She may not understand that need well, since she herself has only one bladder to worry about. But his desperate need for help makes her feel needed and therefore important and therefore provides a sense of purpose and meaning in her life. Suddenly, a medical solution occurs and his desperate need is resolved and he is never again "desperate" in the same way for her help. This can upset both of them emotionally in multiple ways. The mutual effects can reverberate back and forth in their relationship, possibly into a downward spiral into mutual "bed death" misery.

4.3.2.2.8 Loss of Power for the Partner

There can be reverberating power and affection patterns within a couple. When a man loses his prostate, he probably won't have the same type of need for sex as before surgery, which – on the basis of the

principle of least interest[31] – means that his wife loses some of her power in the relationship, including an ability to use sex as a bargaining issue. She may respond in ways that reduce his power in order to re-establish equity[32], perhaps treating her husband as less important, respecting him less, or nagging him more often or becoming more harshly critical. If the husband's sexual interest level was 10 before surgery and hers was 4, if his decreases to 6 after surgery, she may have to decrease her interest to zero, in order to maintain equity and her relative power with respect to her husband. The husband might respond to that by decreasing his efforts at affection and romance, to which she might decrease her responsiveness to his affection when he does try. It would be very easy for a couple to spiral downward in a tit-for-tat loss of sex, power, and affection - replaced by increasing amounts of emotional distance, disrespect, and negativity towards each other. The situation might easily end up with no further sexual interaction for the couple.

4.3.2.2.9 Loss of Sexual Signaling.

Difficulty in having an erection may deprive a partner of a sure sign of sexual interest[15]; in other words, if a man's wife saw that he had an erection, it was almost indisputable that he had a genuine sexual interest; without an obvious erection, the sexual situation is more obscure for the man's partner. Is a lack of an erection mean he has no sexual interest or does it mean that he's has interest but isn't at peak capability? It would be easy for a partner to become confused and be more likely to assume the worst and avoid a sexual experience with their partner.

4.3.2.3 Solutions to Sexual Side-Effects

There are many solutions proposed to solve erectile dysfunction after prostate surgery. In the extreme, there are various surgeries, but those have their own failure rates and side-effects, so I won't detail them here. Primarily, there are two solutions – various pharmaceuticals and vacuum devices (I haven't tried some of the electrical stimulators, so I won't discuss them here). It seems that doing nothing is not a good choice because a lack of erections can lead to tissue scaring and shortening of the penis[33], as well as decreased erectile capability[34]. Let's consider pills first.

4.3.2.3.1 Sildenafil and Related Pills.

(Viagra) and related products (even Niacin, a vitamin) are designed or at least useful for encouraging blood flow into the penis. Seldom mentioned is the idea that eating a heavy meal can direct blood flow away from the genitals, counteracting sildenafil effects[35]. That's not a bad idea, but the primary reason a man can't get an erection after prostate surgery is more related to nerve damage than to lack of blood flow, though surgery can interfere with blood flow – hence many doctors prescribe related products immediately after surgery to encourage repair of damaged tissues through extra blood flow. One study found that use of similar medications in Europe prevented ED after two years in 43% of cases compared to only 13% when medications were not used every other day soon after surgery[35]. My physicians prescribed Cialis for a month after surgery to improve healing but recommended Viagra only before attempting sex (rather than on a regular basis). Penson et al.[18] found that even when 45% of their participants reported that sildenafil helped notably, only 31% reported being able to engage in intercourse, although the percentages improved for those with bilateral nerve sparing (49%) or who were under the age of 60 (62%). Bannowsky et al.[36] indicated that sildenafil only could improve erectile function if the nerve supply

of the penis remained at least partially intact. My experience has been similar in that the success of pills – whether prescription or purchased over the counter – is sporadic and often not worth the actual cost. Some of the pills sold over the radio or from catalogs may be complete scams, just taking money from desperate men. Further research may be needed to clarify interactions between conditions such as diabetes and use of pills with ED.

Some pills may pose a cardiac risk, i.e. tachycardia. When one patient first tried sildenafil, he thought that his grandson was jumping up and down on the floor, two floors up – until he realized that the pounding sound was coming from his own heart, which led his doctors to cut out sildenafil for a time. Another side effect of some pills is that they may take time to work and that time may vary depending on the circumstances and the type of pill. That uncertainty of time can interfere with the idea of having spontaneous sex and one's partner may get tired of waiting for the pill to "kick in", as suggested by a recent TV ad in which the frustrated woman just gives up and goes to sleep on the frustrated man. It is often not clear to RP patients how well sildenafil or related products can or should be used with various nitric oxide pills or with niacin, which has also been used as a proxy for sildenafil. Zippe et al.[37] found that sildenafil worked far better for men who had bilateral nerve sparing surgery than for those with unilateral nerve sparing or none (80% versus 0%) but could take more than one trial for success and often was not successful until after a year of recovery from surgery. In other words, sildenafil may not work at first, but may work later, after RP, for reasons that may not be clear. Others report that the success of sildenafil depends on the degree of nerve sparing – 15% (no sparing), 50% (unilateral nerve sparing), and 71 % (bilateral nerve sparing) and that it may require a 100mg dose to be effective[6]. In summary, success rates with pills may vary as a function of nerve sparing, age, timing after surgery, and couple factors such as a partner's willingness to give the pill time to take effect.

4.3.2.3.2 Vacuum Devices (VEDs)

Another approach is the use of a vacuum device. For example, Carroll[5] mentions this device but does not discuss the complexities of using it. Raina et al.[38] found that early use of VEDs improved sexual response after RP, including low rates of penis shortening and thinning. This device may look easy to use, but looks can be deceiving. One patient had obtained one but threw it away because he could never get it to work. Medical staff may not explain the details of how to use VEDs. First, the patient has to create a vacuum proof seal against his skin, which may mean shaving any areas of contact between the device and his skin, because too much hair can prevent the vacuum from taking hold. Vaseline may be used to help create a seal, possibly without shaving, but, but then it's possible one's partner may not like contact with Vaseline during sexual activity. Second, the patient may need to lubricate his penis so that it doesn't try to make a U-turn back against his body when the vacuum starts to work. Third, he may need to tie off his testicles with a sock or rubber ring or similar device so they are not sucked up into the container. Fourth, it may take several attempts, like stretching a rubber band, to get the best results. Lastly, he may find that the tension holds for only a limited time because a penis ring may not "hold" all the blood back for more than a couple of minutes. There is also a cinch device that can substitute for a penis ring, but it can capture pubic hair (of either partner) and be painful and can be difficult to loosen. Other limitations of vacuum devices include looking better than the

actual tensile strength created and a "cold" sensation for one's partner, compared to the feel of a normally erect penis. Partners may object to vacuum devices for a number of reasons. Use of such a device may seem like a criticism of the partner for not being able to excite the man enough. Use of the device may seem to make sex too "mechanical." The erection produced may not be strong enough for penetration and may not last long enough. It is not clear that the issue of how well pills and vacuum devices might work together has been studied in research.

4.3.2.3.3 Injection therapy

Injection therapy may work for produce erections in 80% of cases[34], even 85%[6] or even 90%[23] but many patients may never try this treatment. One patient who had RP found that the MUSE approach did not work as well as he had expected, which matches the lower 40% success rate and inconsistent results[23], although O'Leary[34] rates its success rate at only 30%. Oncologists may need to consider earlier introduction of injection therapy as an adjunct to other treatments[8] rather than using it as a treatment of last resort (because of its inconvenience and patient rejection[23]) before considering implants or further surgery. Some have offered injections as a second line of ED treatment as early as six months after RP. One study found positive results (43-69% ED recovery by three years post-RP) for injections and drug treatments for men with nerve sparing but not for men who had no nerve sparing[8]. The injection route may work better for diabetics[34]. However, rejection rates may be as high as 50% over two years for men attempting to use injections[39].

4.3.2.4.4 Low intensity shockwave therapy (LI-ESWT)

Low intensity shockwave therapy was not provided to any of the patients discussed here; however, it may have potential for treating ED[40].

5.0 Discussion

One theme that I think is valid, though seldom discussed, is that prostate surgery makes your body's responses much more similar to those of a woman. Your bowel control ends up more like a woman's, without a prostate. Your bladder control ends up more like a woman's, with some leakage almost inevitable on some occasions of stress. Your orgasmic response becomes more variable, like a woman's. Your response is no longer virtually guaranteed, more like a woman's. You lose the ability to ejaculate, a capability retained even by transwomen, if not women themselves. Your interest in having sex may diminish, without the incentive of relief of internal pressures from a full prostate or seminal vesicles, probably coming closer to that of a woman. Since these are my observations, it is not clear that they are so perceived by other cancer patients, leaving a question whether medical caretakers should put this type of thought into the minds of their patients when it might not occur otherwise.

I think there is a tendency for many men to think that there sexual capabilities are so normal, so well grounded, that no surgery could ever possibly diminish them. It is difficult to realize how dependent a man is on the status of his erectile nerves in terms of being able to have an erection. Thus, for the men I have talked with, losing erectile capability after prostate surgery, even if not a complete loss, was still a great disappointment, made even greater when supposedly "sure" cures (pills, vacuum devices, injections, etc.) did not lead to a

complete restoration of pre-surgical capability. This disappointment makes many men at risk for being taken advantage of by radio or flyer advertisements claiming to be able to solve any and all problems of erectile dysfunction or penis shortening by using these or those pills (at as much as $150 a bottle, of course). Medical cancer caretakers should alert cancer patients to these potential issues in advance so the patients are not further victimized financially or emotionally by false hopes from false "cures".

Some might suggest that couples need to communicate about sex. That's true, of course. But while communication about sex is difficult to begin with under normal conditions (because of male/female physical and emotional differences that may be difficult for each gender to understand), it may be even more difficult when, at least from the man's perspective, he is "failing" sexually in comparison to prior to surgery. In a business environment, if a salesperson doesn't "seal the deal" with a potential customer, the boss may demand a discussion to prevent a similar problem in the future. But when there is no "boss", a wife may fear that discussing the issue may further humiliate her already stressed husband and thus, out of perceived kindness, not bring it up. Also, a wife may feel she does not understand the changes caused by or after the surgery and not feel competent to try to discuss them with her husband. One husband I met talked about this with me and shared that he wondered what his wife did think about his damaged sexuality after prostate surgery; he had never discussed this with her even though it was now four years after his surgery. There may be substantial qualitative changes to a couple's sexuality after prostate surgery; to what extent are both the husband and wife willing or able to adapt appropriately? For example, given the extra time that sex may require, would it work to switch off, with sex focused on the needs of just one person at a time? Would it work to reduce the frequency of sex but allocate more time for it when it does occur? Would planning for sex work better or would the loss of spontaneity do more harm to the process? Thus, this is a case of "easier said than done" in terms of helping couples to communicate about these complex issues.

Since my surgery I have wondered "How would I tell my pre-surgery self what it's like to not have a prostate?" Would my pre-surgery self be able to understand? With a prostate, it's like a man wants sex just for the sake of sex (to relieve his prostate), in the same way that someone might want to use the bathroom, not for some lofty ideal or glorious goal, but just to get temporary relief. A woman might want sex to get pregnant, to increase her husband's attachment to her, to catch a financially desirable partner, but how often does a woman want sex just for sex without any other motivations? Is it possible for a woman to understand how her husband might want sex with her for no other reason than to have sex? I suspect many men get married with an assumption that their wife is of the understanding that she has become his solution, his answer to his prostate's frequent sexual needs. But is that the wife's same understanding or not? Is it likely that gay men or lesbian women can attain a more accurate and empathic understanding of each other's sexual needs than can a man and a woman? For example, I have heard of couples where the man wanted sex ten times a month while the wife wanted it maybe once a month. How can a heterosexual couple bridge such a gap in desire and frequency? How can you tell a man, as a woman, that you are just not interested in such a way he doesn't feel bad about such a rejection? How could a woman explain that she was very interested in

flirting, kissing, necking, and maybe even heavy petting, but not all that interested in sexual intercourse? So the man doesn't feel like well, I got led on since her interest level in all the preliminaries seemed as high as mine but when we got to the bottom line, the interest level dropped like a rock, compared to mine? Without a prostate, I am so much more like a woman in the sense that sex has ulterior motives – like proving to myself that I can still do it, even if I am not all that interested per se. That having an orgasm is nice but if I didn't have any for a couple of weeks it would not be the end of the world, like I used to feel it might be? That having sex with my wife might be more to boost her emotions than to make me feel better (without that coming across as patronizing or other negative connotations?). As in, she's so much nicer the morning after, it would be worth doing, even if I didn't have an orgasm at all for myself. Could my pre-surgery self understand such a change? I don't know.

6.0 Implications

6.1 Measurements.

One area that is needed to address recovery from prostate surgery involves improved measurement of personal sexuality and of couple sexuality. In my review of the literature, measures of erectile strength did not make fine enough distinctions despite their importance for understanding the impact of surgery or other conditions; for example, even among men whose scores on the International Index of Erectile Function[34] remained the same before and after RP, only 6.7% of patients reported "that their erections were as good as before the surgery"[41]. Some scales, such as the Erection Hardness Score, focused on hardness rather than adequacy for sexual intercourse[42]. Although penile hardness has a linear and quadratic effect on successful intercourse outcomes, hardness by itself does not measure adequacy for intercourse. Therefore, the JMESS is presented in honor of Dr. Tony Jurich, a professor from Kansas State University who specialized in human sexuality and sexual counseling, but drowned accidentally in 2010 in Mexico. The new scale makes important distinctions in the size and capabilities of a male erection. It should be useful for administration to either heterosexual and/or gay men.

A. The Jurich Measurement of Erection Adequacy Scale (JMEAS)

0 – No erection at all

1 - Partial erection, less than 50% of that prior to surgery

2 - Partial erection, 50% or greater of that prior to surgery, but not adequate for intercourse

3 - Partial erection, barely adequate for intercourse for at least a moment

4 - Erection, fully adequate for intercourse in strength but not for sufficient duration

5 - Erection, fully adequate for intercourse in both strength and duration

A second measurement goal might be to assess a couple's sexual beliefs and practices before surgery to help determine how surgery might impact their sexual life as a couple and perhaps address changing some of their sexual values or perspectives before surgery in order to help preserve their sexual life after surgery. Therefore, the DSBPS is presented as a first attempt to assess some of these important concerns.

B. Dysfunctional Sexual Beliefs and Patterns Scale

All questions would be answered with a Likert-type response pattern of strongly disagree, disagree, not sure, agree, and

strongly agree. The questions can be written for the male cancer victim or the partner. The questions below are for the wife/partner. Agreement with each of the questions might suggest a greater chance of sexual problems after prostate surgery, especially the greater the damage to the man's erectile capabilities. The questions could be given both before and after RP. The responses would be in a Likert-type format – strongly disagree, somewhat disagree, not sure, somewhat agree, strongly agree. R = reverse coded.

1. My husband/male partner does not need much foreplay.
2. Our sexual relationship primarily involves intercourse or anal sex.
3. If my husband/partner could not get a strong erection as part of having sex, it would seriously damage our sexual relationship.
4. If my husband/partner felt like he needed sex a lot less after surgery, that would be fine with me.
5. If my husband/partner were to need a great deal of foreplay after surgery that would be very discouraging for our sex life together.
6. I believe that good sex should be completely spontaneous rather than planned.
7. It would be very frustrating for me to have to wait for some pills to kick in for my husband/partner to be able to have sex with me.
8. If my husband/partner had to artificially inflate his penis with a mechanical pump or similar device in order to have sex that would seem to make our sex life pretty manufactured or artificial.
9. I would not want to have sex with my husband/partner if his penis was cold to the touch.
10. In our sex life, my needs as a wife/partner have pretty much come first before my husband's needs and I'd prefer for it to stay that way.
11. I have an unstoppable, resolute determination to keep our sex life exciting and active no matter the damage done by surgery to my husband's sexuality. (R)
12. I would not want to have to schedule having sex like it was making an appointment.
13. I don't have the time or energy for having sex in the morning even if my husband feels more like doing it then.
14. We have a lot of conflict over how often to have sex; if cancer surgery were to reduce that conflict, I would be very happy, even if we never had sex again.
15. Having conflicts about how often to have sex kind of makes it more of a problem than a benefit.
16. I don't like for my husband to wear anything other than boxer shorts for underwear.
17. Oral sex or manual sex is not really sex in my opinion.
18. Oral sex or manual sex or anything other than penile/vaginal intercourse is morally wrong.
19. My husband is the primary person who initiates sex in our relationship/marriage.
20. With respect to having sex with my husband, I am the person who needs the most foreplay.
21. I would not want to have a type of sexual relationship with my husband in which I had to initiate sex much of the time in order for him to be able to have sex with me.
22. I don't think that men ever really need much in the way of foreplay before sex, especially not nearly as much as women need.
23. I don't think that prostate surgery will change our sex life much at all.
24. My husband's sexual capabilities are so strong, it's hard to imagine that anything

could get in his way of performing adequately.
25. My husband has ED (erectile dysfunction) problems already; it's hard to imagine that surgery would make them much worse.
26. If our sex life disappeared after his surgery, that would be fine with me; it's never meant that much to me anyway.
27. It would not be acceptable to me to have one time just for him to arouse and stimulate me and perhaps another time for me to just focus on him and not worry about my own pleasure.
28. Using a penis pump for "exercise" is just another name for masturbation, which I think makes it morally wrong to do.
29. As a couple, we do not talk about our sex life very often or in much detail.
30. As a couple, I wish we did talk about our sex life together more often or in more detail, but we don't.
31. Sex is something a couple need not talk about much, if ever.
32. If a man cannot produce semen/sperm in order to get his wife pregnant, then sexuality is pretty much useless for his wife.
33. I think sexual intercourse is pretty much pointless if a husband is sterile (unable to produce sperm).

C. Consequences of Prostate Removal and Nerve Damage (Truth in advertising memo)

This checklist enables medical staff and patients to be on the same page as to the possible side-effects of prostate surgery. Not all consequences happen to all men, but likely some happen to all men, at least right after surgery.

1. You will no longer ejaculate; you never will.
2. You will not enjoy the sense of accomplishment that ejaculation provides.
3. If you cannot have an erection, you will not have the thin skin touching that a penis in a vagina provides between two people.
4. If your wife depends on a strong erection for her own sexual enjoyment, she may not have that anymore if you cannot develop a strong enough erection.
5. You may not be able to feel your erection developing in the same easily felt way as before.
6. You may still be able to have orgasms, even if you cannot develop erections.
7. Your sexual response will be more variable, sometimes not so good, other times maybe stronger or longer than before surgery.
8. Sometimes you won't be able to have an orgasm no matter how stimulating your wife/partner may be.
9. You won't have to worry about cleaning up semen after having sex.
10. You won't have to worry about your wife becoming pregnant from having sex with you.
11. You may be able to have orgasms more often than before or closer together than before.
12. Your wife may need to learn, if not already, how to stimulate you manually or orally.
13. You may need a combination of pills, penis rings, vacuum devices, or lubricants in order to have a strong erection and/or orgasm(s).
14. It may take up to five to eight years for your sexual responsiveness to return to "normal" as it was before.
15. If you haven't yet learned how to communicate with your wife about your mutual sex life, you will need to do so now.
16. Your wife may need to develop more of a "cougar" attitude about sex, insisting on it, even if she doesn't feel like it.

D. Prostate Cancer Side-Effects Awareness Scale

1. The undersigned have been made aware of the possible side-effects of prostate cancer surgery, as explained below.
2. The man will need to drink plenty of water and eat high fiber foods on a regular basis and use the bathroom as soon as nature "calls" in order to avoid the risk of severe constipation
3. The man will have bladder control problems that will probably improve over time but may remain with slight leakage under conditions of stress to the bladder, necessitating the use of pads or adult diapers for many years (or other devices).
4. It is highly likely that erection dysfunction will occur at first, which will probably improve, but may remain to some extent for years. Multiple solutions may be needed to restore erection functionality to permit sexual intercourse.
5. In some respects, the man will become more like a (typical) woman, in terms of having difficulties with constipation, bladder leakage, and lower interest in having sex.
6. The man should anticipate and his partner(s) should anticipate the need to discuss the implications and effects of the side-effects of prostate cancer surgery.
7. Good communication will be needed between sexual partners for the man to improve his chances and the couple their chances of regaining a satisfactory sexual life together.
8. We recognize that the effects of aging by themselves may compound the side-effects experienced after surgery and realize that different treatment options may be needed for each type of effect.
9. If the man has diabetes or other complicating illnesses, those illnesses may slow recovery, especially if left untreated.

E. Pre-Surgery Couple Commitment Scale (for more details see Schumm[10]).

1. As a couple, we jointly agree to commit ourselves to the following beliefs and actions with respect to our sex life together after prostate cancer surgery:
2. We will freely discuss any side effects, including bowel, urinary, and sexual ones, that may be experienced.
3. We will discuss the impact of the surgery on our sex life together and commit to taking actions needed to maintain a healthy sexual life together.
4. If sexual intercourse is not possible after the surgery, we will seek to please each other through manual or oral stimulation, as needed, without feeling guilty about the changes.
5. If sexual activity requires more preplanning or the use of special equipment, we will help each other in these areas rather than becoming critical of each other or demanding more than can be realistically offered.

6.2 Research.

There are many unsolved research questions, from both an individual perspective, a partner perspective, and a couple's perspective. One issue is what a patient should expect in terms of the time to recovery. One source reported that nerve repair after RP continues for 6 to 12 months after surgery[43]. It's frustrating to a patient to hear that he should recover completely in six months, which then is modified to a year, which then is modified to two years, then three years, and then four years. The patient may well feel like they are getting the "run-around" even though it may only be that the physicians really don't know how long recovery may take, especially for older

patients. A second issue is the types of over-the-counter pills that may really be of help versus being only another scam to get the money of desperate, impotent men. Literally, dozens of pill ingredients have been hyped as cures for ED (e.g., vitamin B12[35], niacin, vitamin C, vitamin D, folic acid, Alpha lipoic acid, L-Argenine[44], nitric oxide, etc.). Physicians or pharmacists should develop a research-based knowledge of the effectiveness or lack thereof of available non-prescription pills as well, of course, as for prescription medicines. A related issue is the cost of medications; some medications for ED are in the range of $100 per pill/injection, which may be unaffordable for some patients. Veterans may be able to access similar medications at no cost, however.

A third issue is how couple factors might play a role in the recovery of a couple's sexual life after prostate surgery; a start would be made with the above scales being used to predict when couples were able to resume what they feel is a more normal sexual life. Program evaluations should be conducted to determine which approaches to involving both spouses in constructive responses to side-effects are most effective overall or most cost effective. A fourth issue might be how more detailed instruction in the use of vacuum pumps and penis rings might improve the value and actual use of such products, given that some couples have thrown them away because of inadequate training in how to use them effectively. Ideally, a fifth need would be for a cream that could be used externally on the penis in order to elicit a strong erection as that would be much more convenient than using pills, MUSE, or injections. A sixth need for research is to determine how prostate surgery affects gay men and/or gay couples, especially if both partners have had their prostates removed about the same time[29,45]. If men, on average, have more investment in sexual pleasure, then if both men lost some of that capability, would it detract more from their overall relationship satisfaction? Would losing erectile capability impact open gay relationships more or less than closed gay relationships? Some research suggests that loss of the prostate, ejaculation, and erection rigidity may be more detrimental to gay relationships than to heterosexual ones[46]. But clearly, more research is needed in that area.

6.3 Clinical Care.

If sexual side-effects are of concern to a patient, perhaps the patient should be informed, *in advance*, not only of what treatments have the best chance of curing the cancer, but of which treatments have the best chance of preserving urinary or sexual functioning at baseline, or at least patient-acceptable, levels, for the given *age* and other characteristics of the patient. For example, which approach – RP or brachytherapy – might be most effective for a given, particular patient of a certain age? On the one hand, cancer care personnel may not be able to predict with certainty which side-effects may occur for any given patient; on the other hand, they should be aware of the range of possible side-effects. My experience and that of my acquaintances has been that the former was used as an excuse to avoid specific discussions about the latter. The hope was probably that perhaps the patient will not have any of the side-effects or perhaps those side-effects will be of brief duration, so there is not much use raising the patient's anxiety or decrease their hope by going into details. This can lead to a rubber-fence phenomenon. If the patient is told that their side-effect will go away after a year but it doesn't , then it will be predicted to go away in two years. But if it doesn't go away in two years, then it will be set to three years, and so on. The patient can end up feeling like, if this keeps up long enough, I

will die from something else and –from the perspective of the medical staff – "problem solved!" or "Well, his ED is solved now!". I think that the possible side-effects of cancer treatment need to be discussed more honestly and probably provided in written format, since pre-surgery discussions may not be "heard" well, given the patient's high level of anxiety right before surgery. It should not be too hard to say that side-effects vary greatly from one patient to another and in the time to "cure" but here is a range of possibilities. Carroll[5], for example, devoted six pages out of 88 to a discussion of side effects after prostate surgery, with a discussion that seems to assume that different treatments usually are effective; yet among the men with whom I've talked, some side effects have remained for at least three-to-four years after surgery. Carroll[5] stated that less than five percent of men have severe urinary incontinence after radical prostatectomy but doesn't give a percentage for those having moderate or occasional urinary incontinence; likewise, many suggestions are given for overcoming erectile dysfunction, but in what percentage of cases do men recover enough to be able to engage in sexual intercourse on a regular basis? None of my contacts reported being told such details in advance.

Furthermore, our sense is that couple effects are almost never discussed with patients, especially prior to surgery, but that couple difficulties, including female sexual functioning problems, can exacerbate side-effects or even prevent their solution. Thus, we think that partners/spouses need to be a larger part of the discussion of side-effects, their impacts, and their treatment. Physicians or social workers attached to hospitals may need to be more assertive in having sessions with spouses as well as men about how prostate surgery may affect their sexuality as a couple and what adjustments to their sexual life may become necessary, depending on the side-effects. The discussions should include side-effects with respect to bowel habits and bladder control issues and ways to show understanding rather than ridicule of any changes to prior conditions.

Discussion of remedies for erectile dysfunction problems need to be detailed enough to be useful. For example, a nurse might show a man a penis pump and explain the general functioning of it, but leave the patient clueless as to how to actually use it. Some issues to discuss might include how to maintain the vacuum as well as how to start it. Are there pros and cons of using mechanical pumps versus electrical pumps? How much should pumps cost? How many varieties of pumps are there? Where can they be purchased? What do you do if a particular pump fails (my experience has been that they are not always built "ruggedly" and can break easily, even though I have always obtained a free replacement under such circumstances)? How can the pump be used in proper timing with penis ring placement? What do you do if the penis does not retain its level of inflation very long? How does the use of a pump tie into the use of ED pills of various types? Will the use of penis rings deform the base of the man's penis? Can niacin be used safely in combination with pills and/or pumps? How does the tightness or thickness of penis rings vary and what are the effects of such differences? If the pump and rings only maintain a useful erection for so many minutes, how will that impact a couple's sex life? How do such devices impact the apparent spontaneity of a couple's sex life? Cost should not be overlooked. The first penis pump I was offered cost $300 (some may be as high as $700), though there are many versions that are as effective but cost much less, as low as $18.

6.4 Limitations.

The basis of this report is anecdotal, from a few individuals who are acquaintances. Therefore, it cannot be generalized to all men who have had prostate surgery. It may not apply well to men who have had only part of their prostate removed or to men who have elected other cancer treatments such as radiation or chemotherapy. Some of the issues will be more applicable to heterosexual couples than to gay male couples[15]. Some issues might apply to transwomen who have retained their prostate, but whose prostate has become cancerous. The scales that have been proposed need to be tested for reliability and validity before being put into general use. We have not discussed issues surrounding bone health or loss or hormonal effects related to androgen treatments. We have not discussed the many different treatment options available to cancer victims but have focused on side effects related to radical prostatectomy. Some medical centers have found brachytherapy to increase chances of cancer cure while reducing side effects[20]. There are other issues not discussed herein; for example, one patient was scheduled for surgery by his physician before the patient was consulted about a date that would be best for him and his family. That patient didn't want to have surgery done in his home town but felt safer going to a major cancer medical facility. The timing of genetic testing of the prostate is another issue not discussed here; in my case, genetic testing was done after surgery, rather than before; but perhaps genetic testing before treatment might guide the patient's physicians and the patient to a more suitable treatment approach. For example, a Gleason score may not correlate well with the actual aggressiveness of the cancer in terms of the cancer's genetics, another area where more research is needed. Nor has the discussion involved any risks of delaying prostate treatment, if the cancer is deemed aggressive; the patient should be informed of any risks of delaying surgery for two weeks versus two months or ten months, for example.

7.0 Conclusion

Although this assessment is based on only a few cases, the discussion of the details of side-effects exceeds that usually found in the literature, which may encourage greater use of qualitative methods in cancer research. The overriding sense among my contacts with men who had gone through RP is disappointment in that the "cures" for the side-effects were oversold in terms of how quickly body functions would return to normal and the lack of extent to which they returned to baseline as things were before surgery. It didn't seem that expressions of hope for baseline recovery were age-related; the scientific literature seems clear that men over 65 are far less likely to return to baseline but none of the men with whom I have talked about RP felt that their age was taken into account when discussing their chances of recovery from side-effects of RP. This can occur between patients; for example, one man (age 45) encouraged me in terms of total recovery, though at my age (64, diabetic), the research would suggest my chances of recovery were much less than his had been at his age, without diabetes.

There seems to be a tension between hope and unpredictability. That is, the medical staff want to encourage hope and for patients to expect the best possible outcomes, yet, in reality, the medical staff cannot predict with certainty which outcomes will occur for which patients in what time. Furthermore, it is not clear that medical staff are taking concurrent diseases into account above and beyond age (e.g., diabetes), diseases that may reduce the chances of recovery from side-effects. I think more research needs to be done on

surgery regret among RP and other treatment cancer patients, taking both patient and family factors into account. Surgery regret questions should take cancer reduction success into account or focus on regret over side-effects above and beyond cancer cure; otherwise, overly optimistic expressions of success may be elicited.

Some medical support staff may have exaggerated hopes for baseline recovery. I think there needs to be more research on conditions prior to surgery, especially with respect to diabetes or related illnesses and with respect to couple factors. If a partner doesn't believe in any forms of sexual expression other than sexual intercourse, why would that belief change after RP without therapeutic intervention? In other words, partner beliefs can limit sexual activity as much or more than any physiological side-effects of RP, but few research studies have taken partner effects into account. I think that coaching of partners may need to be an important part of any social work with families involved with RP and other forms of prostate cancer treatment; assessment of patient and partner attitudes about sexuality in general may be useful for predicting which cancer treatments will interfere the least with sexual expression in both the near-term and the long-term. At the same time, medical staff may overlook some of the possible sexual gains from RP.

Note: The author is not a medical physician and the contents of this paper should not be construed as medical advice. If the paper raises medical issues about your past, current, or future cancer treatments, please address your questions or concerns to your own medical care provider(s).

References

1. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2019. CA Cancer J Clin 2019; 69(11): 7-34.
2. Prostate Cancer Foundation. Prostate cancer patient guide. Santa Monica, CA: Author, 2019.
3. Mandel P, Preisser F, Graefen M, Steuber T, Salomon G, Haese A, et al. High chance of late recovery of urinary and erectile function beyond 12 months after radical prostatectomy. Eur Urol. 2017; 71: 848-850.
4. Luiting HB, Roobol MJ. The use of PSA, biomarkers, risk calculators and mpMRI in the early detection of prostate cancer. Int Med Rev. 2019; 5(1): 1-20.
5. Carroll PR. Prostate disorders. Berkeley, CA: School of Public Health, University of California, Berkeley, 2020.
6. Ellsworth, P. 100 questions and answers about prostate cancer (3rd. Ed.). Burlington, MA: Jones & Bartlett Learning, 2013.
7. Martel T, Pompe RS, Bandini M, Marchioni M, Smith A, Bondarenko HD, et al. Radical prostatectomy in metastatic prostate cancer: a systematic review. Int Med Rev. 2017; 3(6): 1-9.
8. Sridhar AN, Cathcart PJ, Yap T, Hines J, Nathan S, Briggs TP, et al. Recovery of baseline erectile function in men following radical prostatectomy for high-risk cancer: a prospective analysis using validated measures. J Sex Med 2016; 13: 435-443.
9. Nguyen LN, Head L, Witiuk K, Punjani N, Mallick R, Cnossen S, et al. The risks and benefits of cavernous neurovascular bundle sparing during radical prostatectomy: a systematic review and meta-analysis. J. Urol. 2017; 198: 760-769.
10. Schumm WR. The long-term sexual and urological side effects of surgical removal of the prostate for cancer: A personal perspective from a research scientist. In An ebook on sexual medicine (pp. 1-26). Las Vegas, NV: Openaccessebooks, 2019.
11. Zaider T, Manne S, Nelson C, Mulhall J, Kissane D. Loss of masculine identity, marital affection, and sexual bother in men with localized prostate cancer. J Sex Med 2012; 9: 2724-2732.
12. Rossi MS, Moschini M, Bianchi M, Gandaglia G, Fossati N, Dell'Oglio P, et al. Erectile function recovery after nerve-sparing radical prostatectomy for prostate cancer: is back to baseline status enough for patient satisfaction? J Sex Med 2016; 13: 669-678.
13. Hermann B. Your body, your emotions, your relationship: an interactive guide for understanding sex, relationships, and cancer. Zion, IL: Cancer Treatment Centers of America, 2018.
14. Glickman, L, Godoy G, Lepor H. Changes in continence and erectile function between 2 and 4 years after radical prostatectomy. J Urology 2009; 181: 731-735.
15. Lee TK, Handy AB, Kwan W, Oliffe JL, Brotto LA, Wassersug RJ et al. Impact of prostate cancer treatment on the sexual quality of life for men-who-have-sex-with-men. J Sex Med. 2015; 12: 2378-2386.
16. Frey AU, Sonksen J, Fode M. Neglected side effects after radical prostatectomy: a systematic review. J Sex Med 2014; 11: 374-385.
17. Nelson JB. The ongoing challenge of urinary incontinence after radical prostatectomy. J. Urol. 2017; 198: 1223-1225.
18. Penson DF, McLerran D, Feng Z, Li L, Albertsen PC, Gilliland FD, et al. 5-year urinary and sexual outcomes after radical prostatectomy: results from the

prostate cancer outcomes study. J. Urol. 2005; 173: 1701-1705.
19. Michl U., Tennstedt P, Feldmeier L, Mandel P, Oh SJ, Ahyai, S, et al. Nerve-sparing surgery technique, not the preservation of the neurovascular bundles, leads to improved long-term continence rates after radical prostatectomy. Eur Urol. 2016; 69: 584-589.
20. FC&A Medical Publishing. Your prostate answer book. Peachtree City, GA: Author, 2012.
21. Kretschmer A, Nitti V. Surgical treatment of male postprostatectomy incontinence: current concepts. Eur Urol. 2017; 3(4-5): 364-376.
22. Tai R, Alphs, HH, Krebs P, Nelson CJ, Mulhall JP. Erectile function recovery rate after radical prostatectomy: a meta-analysis. J Sex Med. 2009; 6: 2538-2546.
23. Prostate Cancer Foundation. Prostate cancer patient guide. Santa Monica, CA: Author, 2017.
24. Mulhall JP. Defining and reporting erectile function outcomes after radical prostatectomy: challenges and misconceptions. J. Urol. 2009; 181: 462-471.
25. Sivarajan G, Prabhu V, Taksier GB, Laze J, Lepor H. Ten-year outcomes of sexual function after radical prostatectomy: results of a prospective longitudinal study. Eur Urol. 2014; 65: 58-65.
26. Araujo AB, Travison TG, Ganz P, Chiu GR, Kupelian V, Rosen RC, et al. Erectile dysfunction and mortality. J Sex Med 2009; 6: 2445-2454.
27. Du K, Zhang C, Presson AP, Tward JD, Brant WO, Dechet CB. Orgasmic function after radical prostatectomy. J. Urol. 2017; 198: 407-413.
28. Wittmann D, Carolan M, Given B, Skolarus TA, Crossley H, An L, et al. What couples say about their recovery of sexual intimacy after prostatectomy: toward the development of a conceptual model of couples' sexual recovery after surgery for prostate cancer. J Sex Med 2015; 12(2): 494-504.
29. Simon Rosser BR, Capistrant B, Torres B, Konety B, Merengwa E, Mitteldorf D, et al. The effects of radical prostatectomy on gay and bisexual men's mental health, sexual identity and relationships: qualitative results from the restore study. Sexual and Relationship Therapy 2015; 31(4): 446-461.
30. Simon JA, Pollycove R. Mercy sex: how much is "normal". J Sex Med 2018; 15: S93.
31. Safilios-Rothschild C. A macro-and micro-examination of family power and love: An exchange model. J Marr & Family 1976; 38(2): 355-362.
32. Bagarozzi DA, Wodarski JS. A social exchange typology of conjugal relationships and conflict development. J Mar & Fam Ther 1977; 3(4): 53-60.
33. Perugia G, Liberti M, Vicini P, Colistro F, Gentile V. Use of local hyperthermia as prophylaxis of fibrosis and modification in penile length following radical retropubic prostatectomy. Int J Hypothermia 2005; 21(4): 359-365.
34. O'Leary MP. Erectile dysfunction. Boston, MA: Harvard Medical School.
35. Stephan E. Hypnotherapy for pain management, self esteem, and re-establishing sexuality & intimacy after surgery. Australian J Clin Hypother & Hypnosis 2014; 36(1): 47-60.
36. Bannowsky A, Schulze H, van der Horst C, Seif C, Braun PM, Junemann K-P. Nocturnal tumescence: a parameter for postoperative erectile integrity after nerve sparing radical prostatectomy. J. Urol. 2006; 175: 2214-2217.
37. Zippe CD, Kedia AW, Kedia K, Nelson DR, Agarwal A. Treatment of erectile

dysfunction after radical prostatectomy with sildenafil citrate (Viagra). Urology 1998; 52: 963-966.
38. Raina R, Agarwal A, Ausmundson S, Lakin M, Nandipati KC, Montague DK, et al. Early use of vacuum constriction device following radical prostatectomy facilitates early sexual activity and potentially earlier return of erectile function. Int J Impotence Res 2006; 18: 77-81.
39. Vale J. Erectile dysfunction following radical therapy for prostate cancer. Radiotherapy & Oncology 57: 301-305.
40. Kalyvianakis D, Hatzichristou D. Low-intensity shockwave therapy improves hemodynamic parameters in patients with vasculogenic erectile dysfunction: a triplex ultrasonography-based sham-controlled study. J Sex Med 2017; 14: 891-897.
41. Fode M, Frey A, Jakobsen H, Sonksen J. Erectile function after radical prostatectomy – do patients return to baseline? J Urology 2015; 193 (4S): e774.
42. Goldstein I, Mulhall JP, Bushmakin AG, Cappelleri JC, Hvidsten K, Symonds T. The Erection Hardness Score and its relationship to successful sexual intercourse. J Sex Med 2008; 5: 2374-2380.
43. Hassouna MM, Heaton JPW. Prostate cancer: 8. Urinary incontinence and erectile dysfunction. CMAJ 1999; 160: 78-86.
44. Constabile RA. Optimizing treatment for diabetes mellitus induced erectile dysfunction. J Urol. 2003; 170: S35-S39.
45. Hartman ME, Irvine J, Currie KL, Ritvo P, Trachtenberg L, Louis A, et al. Exploring gay couples' experience with sexual dysfunction after radical prostatectomy: a qualitative study. J Sex & Marital Therapy 40(3): 233-253.
46. Ussher, JM, Perz J, Kellett A, Chambers S, Latini D, Davis ID, et al. Health-related quality of life, psychological distress, and sexual changes following prostate cancer: A comparison study of gay and bisexual men with heterosexual men. J Sex Med. 2016; 13: 425-434.