



Guy Talk | Solutions for the Psychosocial Aspect of Sexual Health After Bladder Cancer

Dr. Matthew: So, we do have high rates of assistive aids. Their problem is they're all set by low rates of ongoing use. This stat, next line here is related to prostate cancer because, of course, there's obviously more research done in that group. But the experience should not be dissimilar for bladder cancer patients receiving cystectomy. Only about 20 to 40% remain sexually active one to five years, that's close to that 30% we've talked about before, despite attempting the use of pro-erectile agents in two or more cases. So it's not people that have just decided to avoid and shut down, but they've lost hope by using the pro-erectile agents and devices, and hence are no longer sexually active. So when we take a look at the treatment algorithm, what becomes very important is that it's not just about taking the pill, that's not going to work. That's what we used to do. The doctor would give you a blue pill and you'd walk off and having no experience with it, not knowing how to utilize it, not understanding a lot of aspects of it, it's unlikely to be


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Problem: Low rates of ongoing use

- The high success rates assistive aids are offset by low rates of ongoing use
- Only **20-40%** of men remain sexually active at 1-5 yrs. post-RP despite access or attempted use of pro-erectile aids/devices (in many cases 2 or more aids) (Hanash 1997; Althof 2002; Hu et al. 2004; Penson 2005)


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ED TREATMENT ALGORITHM


- MANAGE EXPECTATIONS
- AWARENESS OF RESPONSE CHANGES POST-SX
- UNDERSTANDING THE SIDE-EFFECT PROFILE
- HOW TO SUCCESSFULLY INCORPORATE PRO-ERECTILE THERAPY INTO SEXUAL ACTIVITY
- SPONTANIETY AND NATURALNESS
- INVOLVEMENT OF THE PARTNER

successful. So when being prescribed the pill, hopefully, your healthcare professional is engaging with you at the level where he or she can help manage expectations, awareness of the response changes after your surgery. So that you're not, you'd know that prior to surgery, so you're not shocked by it.

Dr. Matthew: Understanding the side effect profile and recognizing that small blood vessel dilators, for instance, for PDE5 inhibitors, with flushing on the face and nasal congestion and a little bit of dizziness can make you think you're having a cardiac event, which is not the case. It's that that's the nature of a small blood vessel dilators. It just, it provides that side effect profile. Also how to successfully incorporate pro-erectile therapy into sexual activity. For instance, if you're doing this you tell your partner that you took a 20 hour pill today, and you're hoping for tonight or not. So that's something to think about as well. Spontaneity and naturalness can be affected. And so there really is the importance of how to overcome that and the involvement of the partner. So that's why we really want to take a look at a biopsychosocial approach. I mainly talked about this, but it's not just getting the pill as I said.

We take a look at the biological aspects to see whether we can help the psychological and how that can help massage the experience so that patients and couples are more successful. The intrapersonal recognizing the role and the potential this can have on a couple, and trying to encourage, having both members of the couple engaged in the process. And then also social-cultural, religious beliefs, cultural values, social norms. And a good comment here is that the majority of this talk does represent heteronormativity. Meaning if there are gay men listening, or bisexual men, or men who sleep with men, please recognize that from a purely biological mechanism it's always going to be similar. And when we talk about couples, there are a lot of similar things to heterosexual couples. But there are differences and thankfully, there's more research in this area in order to inform healthcare practitioners. So there's more sensitive to those populations that might can be considered marginalized.


Body image is also very important. Actually lots of study on the impact of quality of life. The main findings are, that they do reduce global health related quality of life, but also notice sexual problems are highly related to the ostomy in the literature. So what is the nature of that distress over appearance to stress over changes in body functions, odor, leakage, noises, et cetera. Feelings of being less sexually attractive, avoidance of intimate relationships, and feelings of less masculinity, disclosure and shame, grief and loss. Simply put, is the most significant impact on sexual health and can threaten intimacy in this population. So what do we do about it? It's interesting the research suggests there are three key dimensions body image, the first is evaluation. So this is fully integrated body, meaning that this is their natural people approached body images.



Body image Ostomy and Health-Related QoL

- Several studies have examined the impact OF ostomies on HRQoL
- pre-treatment to 10 years follow-up

- Findings include:
 - Significantly reduced Global HRQoL
 - Sexual Problems, Depressive Feelings, Body Image Concerns
 - Worse concerns about illness (ostomy triggering)



Dr. Matthew: What is their evaluation? Feelings of satisfaction or dissatisfaction with their appearance in general. The investment, how important is one ... where does one place physical appearance. And then the emotional experience related to body related evaluations. And you can see this obviously, where some people are less concerned about their physical appearance. Others, for instance, are significantly influenced, eating disorders, arena, have body image issues, of course, eating disorders is much more complex than just that. But you can see that it's a broad continuum. So the intervention is to suggest, can we shift that? Not just don't go quite with the givens that we experience. So a broader sense of appearance, not the ... but patients that's actually assumptions that one has held for so long. Let's just step back question that and reevaluate, can we reevaluate the importance of physical appearance on our overall self esteem?


We have lots of aspects or domains that influence our self esteem, and we cannot necessarily overweight the physical appearance. And more importantly is a real compassion towards self and being aware of that really nasty negative self-critic about one's physical image. Practical interventions, especially in relation to sexual activity. Have your ostomy pouch fit correctly, empty prior to sexual activity, fold the bag and tape it to your abdomen. Your a stoma kept in many bags, change sexual position so that your partner's weight isn't rubbing against the pouch. And there are also patch deodorants.



Ostomy, distress and sexual health

- Distress over appearance – Ostomy and pouch
- Distress over changes in bodily functions
 - – Odor, Leakage, Noises
- Feelings of being less sexually attractive
- Avoidance of intimate relations
- Feelings of less masculinity
- Disclosure AND shame
- GRIEF and LOSS – body integrity
 - Most significant impact is on sexual health
 - and can threaten intimacy







Ostomy and Body Image - Intervention -

Research: 3 Key Dimensions of Body Image:

- 1) Evaluation**
- Broader sense of appearance (assumptions)
- 2) Investment**
Re-evaluate Importance of physical appearance
- 3) Affect**
Compassion for self – beware of the negative critic





Ostomy and Body Image - Practical Intervention -

Leakage

- Having your ostomy pouch fit correctly
- Empty appliance prior to sexual activity
- Fold the bag and tape it to your abdomen
- Consider stoma caps and mini-bags
- choose sexual positions that keep your partner's weight from rubbing against the pouch
- Pouch Deodorant

Dr. Matthew: Loss of libido can also occur. The good news here is that ... or the bad news, good news is that loss of libido is one of the toughest forms of sexual dysfunction to treat. What's important here, especially in men, is that testosterone is probably, not probably, is the single greatest influence on one sex drug.

In terms of treating prostate cancer, we will treat them with what's called hormone therapy, which is the removal of testosterone from a man system. And when that testosterone is removed, that patient invariably will state that they have little or no sex drive. So it's very much connected. The good news is that when we're talking about the cystectomy, most bladder cancer treatments, they do not affect

the levels of testosterone. So there's not a physiological nature of the loss of libido. That of course is accepting chemotherapy where key levels can usually be affected but they recover slowly. So testosterone is mainly responsible for sex drive, the origins of loss of libido and cancer. Bladder cancer is much more complex. It's not usually testosterone related. Fatigue is obvious one, but loss of sexual confidence, learned helplessness equals performance anxiety.

So how do we deal with it? Acceptance, adjustment, adaptation is the idea of recognizing that you are different than you were prior to treatment.

And can we accept that and recognize that, normalize that and then adjust that, really refers to acute adjustment and then adaptation over time.

So the idea is that try to be aware of the hypersensitivity to erectile function or body image. Your thoughts are being very sensitive to what will drive that negative self esteem, and hence, lose libido. So attempt to adjust the process of outcome of engaging sexual activity, allow for the perception of sexual activities being non penetrative based if the erectile dysfunction is a problem. The ability to achieve orgasm even without interaction, bringing pleasure to each other through touch and sensation and broaden your sexual repertoire. And these are comments from couples that were more successful in adapting over time.

Loss of libido (sex drive)




- Toughest sexual dysfunction to treat
- Testosterone levels are generally not affected by treatment
 - Excepting chemotherapy – t-levels usually return slowly after treatment
- Testosterone is mainly responsible for sex drive
- Origins of “loss of libido” in bladder cancer is complex
 - Fatigue
 - loss of sexual confidence, learned helplessness = sexual performance anxiety

Loss of libido (sex drive)



- Acceptance, adjustment, adaptation
- Challenge Hypersensitivity to erectile function or body image
- Attempt to adjust “process and outcome” of engaging in sexual activity
 - Allow for perception of sexual activity as not penetration-based
 - Ability to achieve orgasm even without an erection
 - Bringing pleasure to each other – touch and sensation
 - Broaden your sexual repertoire

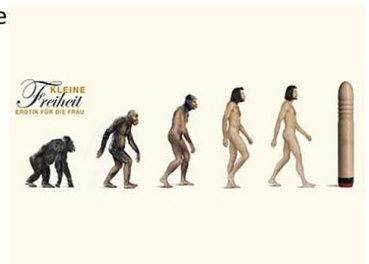
Dr. Matthew: Impact on masculinity. These are the traditional masculine characteristics, we can see sexual prowess plays a big role there. And it invariably has an impact when, it doesn't matter whether you're a manly man or a less manly man when you go into this. When you come out with the sexual dysfunction impact, it has a tendency to affect one's masculinity. And so it's important to process that and recognize that we often have given statements and that our masculinity can be so highly connected to our sexual prowess. And it's just a reminder that you are more than your penis, that a really important part is being a good partner, a father, a caregiver. The surgery cause the nerve damage, it's an organic cause. So it's important to recognize it's not your fault. It's not that you're any less a man, so to speak, that you're having erectile functioning, wrong. It's that we went in and cut nerves that causes erectile dysfunction.




Impact on masculinity

Traditional masculinity characteristics include

- Competitiveness
- **Sexual prowess**
- Dominance
- Self-sufficiency
- Stoicism (control over one's emotions)
- Aggressiveness/assertiveness
- Decisiveness





Impact on masculinity


- Man is more than his penis – (partner, father, and caregiver)
- The surgery caused the nerve damage “organic cause”
- “willpower” can’t bring back your functioning
- you didn’t put up your hand and ask for bladder cancer
 - Having the cancer is not your fault
- Avoid taking ownership of your erectile dysfunction and dealing with it on your own
 - You need help...you are not alone

Dr. Matthew: So no amount of willpower can bring back your erectile functioning, it just depends on whether your nerves can restore. Don't put your, you didn't put your hand up to have the bladder cancer. So try not to take ownership of it as if it's your fault, and you've brought this burden on. It's important to recognize that you certainly didn't put your hand up. Avoid taking ownership, as I just said. And recognize that you can't necessarily manage this on your own. And it's really important to get help, both professional help and help from your partner, you're not alone. Sexual performance, anxiety also plays a role, and it effect arousal plateau and orgasm. It's been known for a long time, fear of failure, fear you're not pleasing one's partner. And of course, if you're having erectile dysfunction as a intermittent response, it can bring that about. The problem is that we start to believe we don't have a lot of control over erectile functioning, then we engage in sometime the level of erectile function and we're so focused on penis.

We're not aware of erotic cues, we're fixated on our own physiological arousal. And hence, the normal erotic cues and touch and feel that we get that would normally stimulate us, we're not focusing on. And then

we can even go global with causing just cognitive distraction on, what have I turned into? What does my partner think? And then that can just cause the sexual dysfunction, erectile dysfunction itself. So the idea is trying to maintain or build one's confidence that they can respond to this in a more successful fashion. Impact on relationships. I mean, patients concerns they're not manly, they're inadequate in pleasing their partner. And this can result in a physical emotional retreat. This is research we did where we follow couples for a very long period of time. Men would say why start what I can't finish and just withdraw.

Partners concerns was far less focused on the loss of penetrative sex, and much more focused on the struggle that they had with the distress related to their partner's retreat. And then they started to take

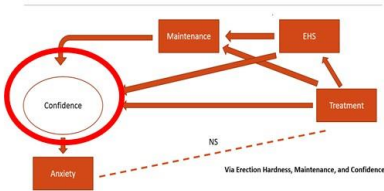


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Sexual performance anxiety


- Posited the interaction between **anxiety and cognitive interference:**
- 1) **Low perceived control**
- 2) **Attentional shift** away from erotic cues
- 3) **Fixated** on one's own physiological arousal
- 4) **Cognitive distraction - global**
- 5) Resulting in feared outcome of ED

Mediation Model



Via Erection Hardness, Maintenance, and Confidence

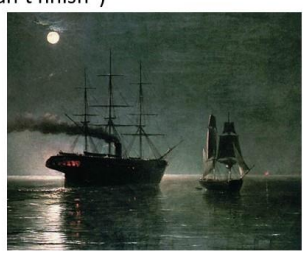
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Impact on relationships

- Patient's concern
 - Not manly
 - Inadequacy in pleasing partner
 - Physical and emotional retreat ("Why start what I can't finish")
- Partners concern
 - Not focused on loss of penetrative sex
 - Distress related to partners retreat
 - Inadequacy in pleasing partner
- Avoidance – not wanting to upset the other





ownership of the problems they were having in their sexual contact, and felt like they were inadequate in pleasing their partner or being attractive to their partner. This can result in avoidance, not wanting to upset one another. And it's like two ships passing in a night. So work as a team. Sex is a two person activity, at least in couples, most of the time. Verbal communication is the key to success. Yes, physical communication is important. But we really want to avoid assumptions, the idea that you're letting your partner down and they're very upset. Those assumptions can really be problematic. So verbal communication.

Dr. Matthew: Remember that, oftentimes, your partner may not be discussing it with you, because they don't want to upset you and vice versa and then that avoidance occurs. Professional help is always available, consider a sex therapist. Believe me, I do not actually expect you to be jumping on the bed like this couple to the right. But I thought it was a little bit optimistic anyway. So that's the end of my talk. A little humor, you know that look women get when they want sex. Me neither. Good old Steve Martin. So thanks again to the sponsors here you can see. And we're available for questions. Thank you very much.

Impact on relationships

- Work as a **team** and support each other
- Sex is a two person activity (at least in couples....most of the time)
- Verbal communication is the key to success
 - Avoid assumptions
- Professional help is available – e.g. sex therapists



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