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Sexual Adjustment to Androgen Deprivation Therapy: Struggles and Strategies

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Abstract

More than half of all men with prostate cancer will be treated with androgen deprivation therapy (ADT) at some point during their lives. Though an effective treatment for prostate cancer, ADT results in profound changes in the man's sense of masculinity and sexuality (e.g., erectile dysfunction, loss of libido, genital atrophy and severe genital shrinkage, hot flashes, loss of muscle mass, fatigue, bodily feminization). These changes usually result in the cessation of all sexual activity. Surprisingly, some couples do find ways of continuing to have satisfying sex despite the man's castrate level of testosterone. Herein, we describe the sexual struggles that couples encounter when attempting to adapt sexually to ADT. A grounded theory methodology was used to analyze interview data. The successful strategies that couples used to overcome struggles, as well as those which seemed to exacerbate struggles, are documented. Couples adjusting to ADT might benefit from knowing which strategies are most likely to result in positive adjustment and which are not.

Keywords

cancer, psychosocial aspects; qualitative analysis; relationships, primary partner; sexuality / sexual health

Prostate cancer (PCa) is the most commonly diagnosed cancer in men. Common first-line treatments for PCa include surgery and radiation which, though effective, are often associated with sexual dysfunction and urinary or bowel dysfunction. These side effects can significantly impact sexual relationships, and thus have been given great attention in the medical literature over the past few decades. Androgen deprivation therapy (ADT) is often administered as an adjunctive treatment, or after primary treatments fail at eliminating cancer cells. The purpose of ADT is to slow the development of metastasized cancer (i.e., cancer which has spread beyond the prostate). In fact, most PCa patients will undergo ADT at some point in their lives (Cooperberg, Grossfeld, Lubeck, & Carroll, 2003; Perlmutter & Lepor, 2007). The development of prostate-specific antigen (PSA) testing has allowed for earlier PCa detection in increasingly younger men, resulting in men being treated with ADT for longer durations (e.g., 10 years; Barry, Delorenzo, Walker-Corkery, Lucas, & Wennberg, 2006; Dacal, Sereika, & Greenspan, 2006; Meng et al., 2002; Smith, 2007).

Despite being an effective treatment for advanced PCa, ADT-related side effects have a profound impact on the lives of cancer patients who are otherwise asymptomatic. The purpose of ADT is to reduce testosterone to castrate levels (i.e., to less than 5% of baseline levels). As a result, the treatment itself is associated with many life-altering side effects (Kantoff, Carroll, & D'Amico, 2002). Distressing physical side effects frequently occur, including weight gain, loss of muscle mass, osteoporosis, fatigue, breast growth, hot flashes, penile and testicular atrophy, profound erectile dysfunction, loss of libido, and difficulty or inability to achieve orgasm. Psychological changes such as emotional lability, increased tearfulness, depression, and cognitive changes can also be very distressing for patients and their partners to adjust to. Often patients accept this fate when consenting to ADT because they feel that participating in a life-extending treatment is worth the life-changing side effects. It is extremely difficult for patients to anticipate the difficulties and understand the experience of such side effects until they experience them; therefore, once patients are on ADT, they often report unexpected difficulty coping.

Physicians have commonly assumed for decades that once a patient is treated with ADT, he will be unable to

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maintain any sexual functioning (Elliot, Latini, Walker, Robinson, & Wassersug, 2010). What is particularly unique about the sexual side effects of ADT as compared to any other treatment or disease-induced sexual dysfunction is that ADT results in significantly reduced or eliminated libido. Furthermore, side effects such as breast growth, hot flashes, weight gain around the hips and abdomen, genital atrophy, and body hair loss are highly emasculating, because they tend to "feminize" the man's body (Elliot et al.; Wassersug, 2009; Wassersug & Oliffe, 2009). Despite a loss of libido, experiencing these emasculating side effects, and being told that it is not possible to have sex while on ADT, many patients still strive to maintain a sexual relationship with their partner.

We developed a model of couples' sexual adaptation processes to ADT previously (Walker & Robinson, 2011). Three distinct patterns of sexual adjustment emerged in a grounded theory analysis. One group of couples had assumed sex to be impossible after commencing ADT, and quickly accepted the loss of sex in exchange for an ostensibly life-extending treatment. Another group was found to be struggling to either maintain satisfying sex or adapt to the loss of their sexual relationship. The third group initially struggled, but were able to become satisfied with their sexual outcome. A subset of these couples successfully adjusted to changes in the man's sexual function and found satisfying ways to be sexually active. The remarkable finding of this study is that although it was challenging, some couples were able to maintain a satisfying sexual relationship while undergoing ADT.

Maintenance of sexual intimacy is an important life-affirming activity that has been shown to have a variety of health benefits (e.g., better mental health, proper hormonal functioning, cardiovascular health, improved metabolism, and musculoskeletal health; Brody, 2010). Maintenance of sexual intimacy has also been shown to act as a buffer against the negative effects associated with declines in health, marital quality, and marital satisfaction (Harper, Schaalje, & Sandberg, 2000). Increased sexual dysfunction has been found to be associated with poorer quality of life, greater mood disturbance, poorer relationship satisfaction, and a lack of marital stability (Boehmer & Babayan, 2004; Clark & Talcott, 2001; McCarthy & Fucito, 2005). Therefore, sexual activity is an experience accompanied by many potential benefits that should be encouraged in those patients who are interested in maintaining it.

With the growing appreciation of the profound ways ADT can affect the lives of men and their partners, there are now efforts to help couples better manage adaptation to ADT (Elliot et al., 2010). Building on the previous report that some ADT patients are successfully able to maintain a sexual relationship, in the current article we present the struggles that these couples faced when trying to adapt sexually to the side effects of ADT. A detailed description of this process, including the various strategies that couples used to overcome these challenges, is presented.

Method

Eighteen heterosexual couples were recruited from a tertiary care cancer center, a national patient advocacy group, and through colleague referral. The regional health ethics board approved the study protocol, and informed consent was obtained from all participants. The first author conducted an unstructured interview of approximately 1 hour in length with each couple. Participants were asked one broad question that encouraged them to reflect on any changes they noticed after beginning ADT. They were asked how these changes might have affected their relationship, as well as how they adapted to these changes. The couples were also asked to compare their current experiences adjusting to ADT with any experiences adjusting to prior surgical or radiation treatments. The open-ended nature of the interviews resulted in the couples directing the discussion content. Participants were assured of anonymity and encouraged to be open and forthright during the interview. Eligibility criteria required that all participants were on ADT for a minimum of 3 months, were not concurrently receiving other PCa treatments (e.g., radiation, surgery), and had a female partner with whom they intended to be, or previously were, sexually intimate. For the purposes of the study, sexual activity was defined as any sexually intimate contact with the intent to produce sexual pleasure and arousal. This definition included not only intercourse but also any activity that might be typically thought of as foreplay. Couples also self-identified as satisfied or dissatisfied with the state of their sexual relationship. Those who were "satisfied" had resolved most or many of the struggles they had experienced. Couples who were dissatisfied continued to experience struggles at the time of the interview.

The participating couples represented a wide range of ages, relationship duration, time since treatment, and sexual status. Patients ranged in age from 47 to 83 years, and their female partners ranged in age from 32 to 82 years. Sixteen couples had been married for between 1 month and 60 years, and 2 couples were dating (1 year and 5 years); the mean duration of relationship was 33 years. Patients ranged in length of time since diagnosis from 8 months to 15 years. The length of time on ADT ranged from 4 months to 13 years. Half of the couples ($n = 9$) reported being sexually active at the time of the interview, whereas the remainder of couples ($n = 9$) were not sexually active at the time of the interview.

The interview content was analyzed using a grounded theory methodology (Strauss & Corbin, 1998). Recruitment, data collection, and analysis occurred simultaneously. Participant sampling continued until saturation was

determined, and thus the study included a sample size of 18 couples. Interviews were audio-recorded and transcribed verbatim. A qualitative computer software program, NVivo 8 (2009), was used to aid in the coding process. All interview data was first coded line by line to generate a comprehensive list of themes. All codes were then organized hierarchically, at which point relationships between the themes emerged. Codes were identified as they directly described the phenomenon occurring in the participant quote. Participants' accounts were used as the sole source of data, and all subsequent analysis was carried out on this presumption. Both authors consulted throughout the coding process to ensure that the codes were determined in a reliable manner. To increase confidence in the validity of our findings, a summary of the determined themes was provided to study participants. Participants were invited to review and make comments on the results prior to the composition of the research conclusion. Selected quotes included in this article were edited for readability and to protect participant confidentiality (Morse, 2007).

The intent of this study was to develop a theory about the nature of sexual adaptation after ADT. The aforementioned theory (Walker & Robinson, 2011) about couples' sexual adaptation to ADT is what emerged from the current study. Rather than reiterate this model, readers who are interested in the detailed theory are referred to this previous article. The aim of the current article is to present the specific struggles experienced by couples who maintained and those who stopped engaging in sexual activity.

Results

During the analysis, a variety of categories of sexual struggle were identified. Not all couples experienced all of these struggles, and some couples overcame one struggle only to encounter a new one. For example, some couples overcame the struggles that accompanied a decision to stop engaging in sex by changing their minds and attempting to resume sex. These couples then had to face the struggles associated with trying to have sex while the men had castrate levels of testosterone. Regardless of their decision to maintain or cease sexual activity, all couples experienced struggles. Some were successful in finding solutions to their struggles, and at the time of the interview these couples were identified as being satisfied with their sexual outcome. Couples who were still experiencing unresolved struggles at the time of the interview were identified as being dissatisfied.

Types of Struggles Experienced

The struggles documented in Table 1 can be conceptualized in three categories. Each of these categories is described in detail below. Some struggles were relevant to couples who maintained a sexual relationship, whereas some were relevant to couples who stopped being sexual (see note in Table 1). The first category, adjusting to changes to sexual relationship, included changes to sex, fatigue, and absence of sex. Changes to sex and fatigue presented challenges, and as a result made the maintenance of sex more difficult. Couples who had decided not to maintain sex had to cope with and adjust to the absence of sex. Nonmutuality, the second category of struggles, included expressing affection, connection/withdrawal, willingness to engage sexually, initiation of sex, his libido, experience of pleasure, and her libido. The struggle to preserve a sense of mutuality or balance clearly pervaded many aspects of couples' sexual relationships. Couples struggled with nonmutuality because there was an assumption that it was important for them to be equally contributing to all areas of their sexual relationship. The third category, attitudes and perceptions, was comprised of doubt, grief, decreased self-esteem, and negative attitudes toward sex. Issues that surfaced on an individual level relating to one's attitude or emotional state also negatively impacted the couple's sexual and intimate experiences.

Adjusting to Changes to Sexual Relationship

No couples shared that their sexual relationship had remained the same since undergoing ADT. Whether they persevered through changes to sex or ceased being sexual and adjusted to the absence of sex, couples struggled to adjust to changes to the sexual relationship.

Changes to sex. In response to the changes in men's sexual function as a result of ADT, couples experienced many changes to the ways in which they engaged in sex; in consequence, the nature of sexual and intimate experiences had to be renegotiated. One partner described embracing new experiences: "We [now] like having nice dinners, we like having a nice bottle of wine. I still like to somehow get involved sexually, even though it doesn't involve intercourse." Often this process included changing the goal of the sexual encounter from orgasm to experiencing other pleasurable sensations. One patient shared,

> Libido per se is the start point, but the ultimate point in the encounter is the orgasm, and I can't achieve orgasm no matter what I do; so that part is missing. The carrot at the end of the stick is gone. So you might get the erection, but that doesn't lead to the orgasm. It just leads to the pleasurable sensations that you get from penetration.

The patient's partner shared the sense of loss that she and her husband experienced as a result of the changes that

Table 1. Strategies and Struggles Experienced by Couples Adjusting Sexually to ADT

Category	Struggles	Strategies to Overcome Struggle	Exacerbating the Struggle
Adjusting to changes to sexual relationship	Changes to sex*	Embrace new experiences Acknowledge loss and grief of previous sexual relationship Focus on intimacy Use of erectile aids/sex toys Remain lighthearted and laugh Both partners participate and enjoy the sexual experience Look for positive changes	Hold on to the idea that sex has to be as it was Assume that sex of a different nature is inferior Judge the other person's attempts to improve the situation or to adapt the sexual encounter
	Fatigue*	Make sex a priority Schedule activities earlier in day Allow lots of time for activities Engage in modified/assisted sexual activities	Fail to engage in sexual activity because of fatigue Persist in having sex late in the evening when energy is low
	Absence of sex^	Replace sex with other activities Find other ways to maintain intimacy Reprioritize	Fail to share other interests/activities Fail to maintain sense of intimacy
Nonmutuality	Expressing affection*^	Open and honest communication Increased effort on the part of the patient to show affection Increase direct/perceivable affection	Assume that stopping sexual activity means stopping physical affection Assume that any physical affection will always lead to sexual activity
	Connection/ withdrawal*^	Open and honest communication Persist in keeping patient engaged Try to understand one's partner's perspective Willingness to be vulnerable	Ignore withdrawal Respond with own withdrawal Assume the patient's loss of interest in sexual intimacy is because he no longer desires his partner, rather than an effect of treatment
	Willingness to engage sexually*	Open and honest communication about expectations and assumptions Be open to new experiences Be mindful of the many benefits of sex	Expect experiences to be unchanged Assume that physical arousal/interest is the only reason to engage sexually
	Initiation of sex*	Share responsibility for initiation Communicate about expectations Increase efforts made at initiation Schedule specific times for sex	Wait for the other person to initiate sex Wait for spontaneous sexual desire
	His libido*	Increase both partners' efforts to increase the patient's libido Engage sexually without waiting for physical arousal Focus on partner's intact libido Consider the use of sex toys/erectile aids if both partners are comfortable Engage in sex for reasons other than sexual desire (e.g., penile rehabilitation)	Assume that enjoyable sexual experiences are initiated by libido Put responsibility for sexual initiation on the patient only Maintain rigid assumptions about "how sex should be" Assume the patient's loss of interest in sexual intimacy is because they no longer desire their partner, rather than an effect of treatment
	Experience of pleasure*	Be open to new experiences Redefine experiences of pleasure Acknowledge that the source of pleasure need not be the same for both partners	Maintain rigid assumptions about "how things should be" Expect experiences to be unchanged
	Her libido*^	Partners distract themselves from sexual desire that is not acted upon	Expect his libido to cue the same amount of sexual activity the couple is used to

(continued)

Table 1. (continued)

Category	Struggles	Strategies to Overcome Struggle	Exacerbating the Struggle
Attitudes and perceptions	Doubt*^	Open and honest communication Express doubt and seek reassurance Check out assumptions	Ignore doubt Fail to seek clarification/answers Withdraw from partner Make assumptions Avoid talking about difficult topics
	Grief*^	Acknowledge grief and loss Actively grieve/mourn losses Talk to each other about grief Seek professional counseling Allow time to pass	Ignore grief/loss Feelings of guilt about grief Withdraw from others
	Decreased self-esteem*^	Seek a shared understanding with one's partner Seek clarification from partner about misperceptions Make a special effort to reassure each other Maintain a sense of humor	Maintain rigid assumptions about self-worth Withdraw from others
	Negative attitudes toward sex*	Focus on the partner's experience rather than ones' own Be open to new experiences Expect new sexual experiences to be different from the old ones Maintain an open mind and positive expectancy	Focus on losses during the sexual encounter Compare current experiences with previously enjoyed experiences Expect experiences to be unchanged Ruminate

*These struggles were experienced by couples that were sexually active
^These struggles were experienced by couples that were not sexually active

occurred to their sexual relationship. She stated, "He grieved the loss of what had been, and he certainly grieved for me in the midst of my grief, because it was profound." For her, acknowledging that loss and being able to grieve over it was an important part of her adaptation.

For couples that viewed sexual activity as the best means to connect intimately, this intimacy could not be adequately replicated in any other way. For those couples, to stop having sex would mean to stop being intimately and emotionally connected. For example, one patient described, "I think it brings couples closer together, it keeps them together. It's a part of their love. It's part of life." His partner shared, "I think it's a part of who you are, to share this with your partner, and maintain it, as best as you can." Therefore maintaining sex, despite changes, was the best way for them to maintain intimacy.

Almost half of the couples volunteered information about using or attempting to use oral erectile medications, erectile aids, or toys to restore sexual activities. Although not all reviews were overwhelmingly positive, these methods were still appreciated by many couples; for example, one patient reported his success in using injections to induce erections:

> It was encouraging that you could create it [an erection] at about a 99.9% success rate. Only once or twice has it not worked, so the injections are pretty foolproof, for me anyway. So it's great because you can rely on that. It's been a positive, very positive thing.

A woman described what it had been like to change sexual activities to incorporate the use of a sex toy with her partner:

> I always touch him when he's touching me. Even if he doesn't get an erection, I still need to feel him. Even though we're playing with a toy, I don't find it enjoyable unless I fantasize that it's actually him.

Although the sexual experience was different in terms of objects or aids, the key to success, as described in greater detail below, was that it remained mutual, whereby both partners participated and enjoyed the experience.

Another helpful strategy was remaining light hearted and laughing about the changes to sex: "We laugh a lot more when we make love than we ever did before. I think that's actually added a huge dimension to our lovemaking." The same woman described a time when she attempted to increase romance in their sexual encounters:

> I bought some sexy underwear, and I just laid a path [of rose petals] through to the bedroom. It obviously didn't change his libido but it led to a lot of laughter, and that seems to have been a huge factor.

Trust appeared to be an important factor that allowed her to try these new experiences, and even to laugh about them.

A few couples reported changes that made their sexual experiences more positive. One partner explained that sex before ADT was often impeded by the patient's tendency for premature ejaculation, and that ADT had allowed for increased endurance and sustained activity:

> It's better, because the way it used to be, before this happened, he was very fast with the ejaculation part of it. He would kind of have to hold it for me, and it was kind of hard for him.

Another partner shared how she appreciated being able to focus on touch and physical affection without it always having to turn into something entirely sexual: "I love the cuddling, I love the touch. I would actually say that that's one of the gifts at this time: there hasn't been the sexual urgency with the reduced testosterone." Another couple actually reported that their sexual experience became more spontaneous rather than habitual because the partner became responsible for initiating sexual encounters. Still another couple described how they started sharing sensual massages instead of engaging in intercourse: "I would say that the massage itself can be as much, or more sexual, both in the giving and receiving. I feel a whole lot more intimacy than, than when it was focused on moving to a sexual place." This was a new and enjoyable experience for them instead of sex.

Fatigue. Patients frequently reported experiencing burdensome fatigue, which is a common side effect of ADT. As a result, couples struggled to find the energy to engage in sex. Fatigue impaired the men's physical capacity to engage in sex, as well as their motivation to initiate or respond to their partner's initiations for sex. Couples who successfully accommodated fatigue were those who made sexual activity a priority. Scheduling sexual activity for earlier in the day allowed couples to avoid waiting until late evening, when they were too tired to initiate or to enjoy sex. Setting time aside also ensured that the couple would have adequate time to engage in those activities. Some couples modified their sexual experiences and used sexual aids (e.g., sex toys or vibrators) to increase sexual stimulation, thereby avoiding excess fatigue.

Absence of sex. Couples that decided not to maintain sexual activity often struggled with the loss of their sexual relationship. Replacing sex with another valued intimate activity seemed to be a common strategy that, although challenging, allowed couples to maintain relational intimacy and to be satisfied with their relationship after eliminating sexual experiences. For example, one woman reported,

> We can't do this [sex] anymore, but let's find something that we can do to replace that. We try to always have something planned to look forward to, like a little holiday, or going out to a dinner theater, live music, or something like that. That maybe replaces some of those other activities, but still we get a lot of pleasure and enjoyment out of it.

The strategy of several couples was to consider that sex was no longer a priority. Although it might be assumed that age could play a role in whether or not a couple considers sexuality a priority, people in a wide age range made similar statements. A man in his 60s reported that he got used to the idea with the passage of time: "After about four or five months [of ADT], I had just kind of forgotten mostly about any kind of intercourse. [It] didn't really bother me that much." Another couple in their late 50s explained this change in their lives: "And it's not that we're not close, it just isn't a high priority in our lives anymore." Another woman in her early 40s reported, "The reason it didn't really affect us that much is because there are other parts to the relationship. That's just one little part of it, and we were able to bypass it." When discussing how a person adapts to not having sex, she further stated, "We're too old for that."

Nonmutuality

In general, the concept of nonmutuality refers to the reciprocal nature of intimate relationships. When partners perceived that they were either more or less engaged in a sexual or relational experience than their partner was, they became uncomfortable. Nonmutuality can be separated into several specific themes.

Expressing affection. Despite the variety of ways in which affection can be expressed (e.g., verbal affirmation, physical touch and caress, acts that show appreciation), partners often expressed that their relationships had suffered from a loss of expressed affection. Challenges in expressing affection appeared to affect the partner more than the patient. Partners usually continued to exhibit affection in the same way they always had, whereas displays of affection became less common from the patient. For example, one partner was distressed by the fact that her husband rarely made an effort to express affection, and reported that without intercourse as a clear indication of his attraction to her, she began to doubt his feelings for her. She acknowledged that although he did do things to show his affection for her, such as preparing dinner or bringing home flowers, she was not assured of his affection for her: "When he does do things to show me he loves me, it's because I've had to get angry about it. If he just took the initiative on his own, without having to be told." When

these couples stopped having sex, expressions of affection seemed less meaningful.

Not all couples reported that ceasing intercourse was accompanied by fewer expressions of affection. For example, one partner feared that with ADT, her husband might change his affectionate behaviors: "I was relieved that he still wanted to cuddle, kiss, and tell me he loves me. I thought that if the libido was gone, that all that good stuff would be gone. But it wasn't, so that was great." One patient reported that he

> would like to have it [sex] just for her satisfaction. Being around her, cuddling her, putting my arm around her or giving her a kiss, or doing something for her, to me, is far more satisfying than the sexual act.

In fact, a few couples indicated that some advantages came with ADT. For example, one woman reported, "He's full of romance. He loves to be mushy. I think that helped him to adjust. He's a lot more romantic than he used to be." Another partner shared that her husband became more vulnerable and responsive with her:

> We probably had some of the closest times, with the increased vulnerability that he has allowed himself to have. I think part of that is the shift in hormones. There's a softness there, and a "taking in" of the love that I think I've always expressed, and to my touch. He's very responsive, more responsive than he's probably ever been in all of these years.

Connection/withdrawal. Couples reported that as a result of decreased physical and sexual expression, they began to withdraw from each other. Most difficult was the man's tendency to withdraw from his partner, and the partner's accompanying feelings of isolation. This imbalance in connection to each other became a significant challenge that affected a couple's sense of intimacy. One patient reported, "Not having a good sex life or not being able to, either one of us, to initiate it, really made me withdraw." For some men, withdrawal was associated with feelings of depression: "He went into a depression. He just kind of cut himself off altogether. He didn't talk to me at all. He would answer me if I spoke to him, but he didn't initiate any conversation at all." These couples often reported reaching an impasse, at which discussion became too challenging for them:

> You know the general conversation that goes on between you, none of that was happening. There was just nothing. It was like dead space. Dead air between us, you know? And I felt like I had to always instigate the conversation, and I found that hard work, especially when you don't get anything back.

To avoid isolation, the women tended to facilitate conversation, and were particularly persistent in making a conscious effort to engage their partner in discussion: "[When he's] not quite as communicative as he usually is, that concerns me. So usually I'll say something: 'What are you thinking about?' or 'What's bothering you?'" Trying to decipher what their partner was experiencing was an important strategy to help consider things from his perspective. One woman shared,

> I spent a lot of time really trying to get an understanding of what's going on for him, so that I can look back and understand. So that next time it comes up, maybe we can not go into the same ugly places.

The women were better able to try to reestablish a connection with their partner when they understood his reasons for withdrawal. This exercise in perspective taking allowed women to see that his withdrawal was not a comment on her as a partner, but rather a reaction to a loss of physically intimate connection.

Many men indicated that when they reciprocated in the conversation, they often felt better, because they were able to "get it off their chest." It is possible that discussion was initiated because the women felt they were lacking intimacy, or because they saw discussion as a way to grieve for their losses. A second possible explanation is that communication filled a need to reassure each other of their love, despite a lack of physical intimacy. Those who were able to recover from or to prevent patient withdrawal indicated that although it was challenging, they found a way to maintain communication. They continued to specify that, although the loss of sex and their adjustment to ADT were not pleasant to talk about, and often created in them a sense of vulnerability, they discussed it anyway. Those who did not manage to communicate successfully often continued to struggle with withdrawal and/or isolation. In turn, those couples that communicated openly were more likely to be those who were successful at establishing affection. This illustrates how some areas of struggle are related to each other, and how resolving one through communication (e.g., connection/withdrawal) could also help lead to a solution in another (e.g., expressing affection).

Willingness to engage sexually. Many women perceived that there was also an imbalance in willingness to engage in sexual activities. They reported difficulty in "asking" their partner to participate in sexual activities. They indicated that they were embarrassed to have to "ask" for sex,

and struggled with the thought that, if they had to ask him to participate, he must view sexual activity as a chore. The following exemplar illustrates the layers present in one woman's thought process:

> When he does help me out [sexually], I almost feel like I've had to ask him, because we've had to resort to using a toy now, and I almost feel like I'm being selfish. And I'm worried about us using a toy, like how does that make him feel?

The woman quoted above described engaging in sexual activities in which she began with self-stimulation; however, she required his "help." Having to ask him for help was associated with the fear that she was being selfish. She also expressed concern for her partner's self-esteem and how it could have been affected by their having to "resort" to the use of a sex toy. In contrast, the patient responded to her concern by saying, "It's fine. I'm fine with it because I know I can't get an erection, I'd rather satisfy my partner." Still, she struggled, despite his reassurance that he was "fine with it":

> I know that a lot of the time he doesn't want to do it, so I basically try to keep it to a minimum, because there's times where maybe even three times a week that I would, you know, be satisfied, but I've limited it to probably once a week, sometimes once every two weeks.

Couples who were successful at balancing their willingness to engage in sexual activity were open and honest about their expectations or assumptions. For example, the woman required reassurance that the man was still willing to engage sexually, despite his loss of libido. Sexual experiences often looked different than they used to; therefore, couples could no longer rely on the same sexual script that they were used to prior to PCa treatment. Couples required explicit communication about what experiences were and were not enjoyable. They also had to remind themselves of the benefits of sexual experiences, and to recall what it is they valued about the sexual experience (e.g., pleasurable sensations, importance to their partner, physical connection, the establishment of intimacy).

Initiation of sex. Couples struggled with changes in patterns of the initiation of sex. Couples could no longer rely on the man's spontaneous sexual desire to motivate their sexual encounters. For example, one partner pointedly described her husband's lack of interest in sex: "He said if he had a choice between having sex with the most beautiful woman in the world and having a salad and he was hungry, he would go for the salad any day." It was important for this woman to understand that her partner's lack of initiation of sexual activity was not because he was not attracted to her; it was simply a result of the ADT. Successfully maintaining sex was associated with a shift in who was responsible for initiation. For example, one partner described, "I took over the role of initiator, which has been wonderfully freeing for both of us. It has added richness to our intimacy and allowed him "off the hook" to start what he has no inclination for."

Several women reported that they felt they were putting in more "effort" than their partners. In many cases, sexual encounters became one-sided:

> I've gone through a period of anger about it, where I felt like I was the only one bringing anything to the table. In reality of course, I am. I am the only one bringing anything to the table, but it didn't stop me from feeling angry about that loss.

Another woman shared how she became uncomfortable with this imbalance: "I can't satisfy his needs any longer, so basically what I'm doing is asking him to satisfy me." Still another woman described the thoughts she struggled with during their sexual experiences: "I'm thinking, he can't do anything and here I am getting all the pleasure. It's just for me, and I just think it's only making him feel worse. It's just a reminder of what he can't do."

Another strategy to prevent an imbalance in initiation was to schedule a specific time for sexual encounters. One couple scheduled one morning a week for sex. She described,

> We'd have a long leisurely breakfast. He would go and inject, we would make love, and then would go out for lunch. So the whole day, we would try to set aside for ourselves, just to be a couple together.

Patients who remained sexually active despite a lowered libido had to make a point of putting more effort into the sexual experience. Increased mutuality in the effort put into sexual encounters helped couples to notice that sex was a priority for both patient and partner. The more the experience became unilateral or one-sided, the more difficult it became for couples to maintain sex.

His libido. One patient explained how the loss of mutuality between his and his partner's libido made him less willing to initiate sex: "I started to avoid touching her, because she would think I would be interested when I'm really not. And then [she] would get all hot and bothered, and I'm not. It's bad, [because] you don't want to start anything." He stopped initiating any physical affection because he assumed that it would lead to sex. In this case, he was reluctant to have sex because of his lack of libido. One woman talked about how she learned not to act on

her sexual desires because of her husband's loss of libido: "I would have felt like it, but knowing how he was, I would not have gone ahead and suggested anything." Another woman reported that it was just too much work to try to get her partner interested in engaging in sexual experiences with her. She realized that sex was really the last thing he was interested in, and for his sake, she would find a way to "live without sex." Couples that maintained sex despite a loss of the patient's libido were those who improved efforts to increase the patient's libido, those who engaged sexually regardless of their lack of libido, and those who focused on their partner's pleasure.

Some men talked about the possibility of using sex toys as sexual aids to improve their partner's sexual experience. Although some partners were satisfied with this, others were not receptive to the idea because of a perceived lack of mutuality in the use of sex toys (i.e., they only focused on her, not him). For example, one patient suggested that he could please his wife while using a sex toy: "She would play with me and nothing happened. I could play with her, you know? It's different. [Laughs] Or, [I] could go out and buy one of those artificial deals, like . . . you know?" She responded, "But then I can't see the point of it, because he doesn't have any desire for it. That was the end of sex." This strategy worked for some couples, but not others; success depended on the couple's perception of mutuality.

Most couples that actually maintained sex despite the patient's loss of libido had to move beyond libido to motivate sexual experiences. For example, one partner, who wasn't sexual with her partner before his PCa treatment actually became sexual with him in an attempt to decrease the probability of losing his erectile function while he was on ADT. She said, "When all of this was happening I could see that it was so important to him. I wanted to facilitate that." In light of this, she engaged sexually for his benefit, and although both partners were actively trying to enjoy a new kind of sexual experience with each other, at the time of the interview they still reported a great deal of struggle and dissatisfaction.

Experience of pleasure. Several women reported that they struggled with an imbalance in pleasure. They expressed a strongly held belief that they should not be the only one receiving sexual pleasure. Therefore, these women subscribed to a dichotomous line of thinking in which both partners must equally enjoy the sexual experience for sex to be considered worthwhile. For example, if she was to orgasm, and he was unable, she would consider the sexual experience unfair or unequal. When sexual activities focused specifically on her pleasure, one woman recalled, "I even felt bad because I want him to enjoy it as much as I do." Another woman reported her response to her husband's sexual initiations: "I don't. I shut down completely. I just don't want to, even when he says, "Oh, I'll, you know, give you an orgasm" or something. I don't want to, I just, I just . . . ." This was shown in a tendency for many of the women to decide that their relationship should no longer involve sexual activity if the experience of pleasure was unequal or nonmutual. In most cases, a sexually uninterested husband did not dispute this decision, and the couple became nonsexual. Many women appeared to be so uncomfortable with sexual activity that only focused on their pleasure that they preferred to stop sex rather than have sex that was not mutually pleasurable. One woman overcame her discomfort with nonmutual pleasure by accepting her husband's assurance that he gained great pleasure by seeing how much pleasure he brought her. She became willing to engage sexually when the experience of pleasure became mutual. For women who stopped having sex, a new challenge was to cope with their continuing sexual desire that was no longer satisfied or expressed through sexual experiences.

Her libido. For couples that stopped having sex because of the patient's loss of libido, a real challenge existed for the partner in trying to cope with her still-present sexual desire. These women described how challenging it was to ignore or disregard their own sexual desire or arousal. Only the women expressed this as a struggle; the patients themselves were often unaware of the struggle their partner was facing. The partners described strategies such as "keeping busy" and "distracting" themselves. One partner joked about having to "take a cold shower." Others described "drawing a line" when it came to sexual thoughts:

> You have to . . . learn to put it aside, I guess, and go on. I find that if we, or if I do try to become, well, sexually active, it's sad, because you just, you can't get anywhere.

> I have a mental block. I just know that it won't work, and I can't have that.

Some couples successfully employed this putting-sexual-thoughts-aside strategy: "It's like, quitting smoking. After a period of time you just . . . don't think about it. And if you do, it's, it's not going to happen."

No women in the study expressed being comfortable with self-stimulation or masturbation. Women who mentioned this as a possibility also expressed that they were uncomfortable with it, felt guilty about it, or were not interested enough to put the effort into it. As a result, those who could not be sexual with their partner were often not sexual at all. Furthermore, couples who were able to successfully negotiate redefined sexual experiences, as well as adapt to changes in initiation of sex, were likely to

avoid the problem of her libido, because it was mostly one experienced by nonsexual couples.

Attitudes and Perceptions

Couples reported that they were plagued by unhelpful attitudes and perceptions. Efforts to overcome these barriers allowed the couples to focus more on the continued development of their relationship rather than to get stuck in the experiences of doubt, grief, reductions in self-esteem, and negative attitudes toward sex.

Doubt. Without their sexual relationship as evidence, some partners began to doubt that they were still physically attractive to their partner. Some women even reported doubting that their partner was still in love with them:

> There's times where I could just eat him, I just love him so much. It's really hard because, I don't know if he does. I doubt that he's that close or has the same feelings [toward me]. I doubt it all the time.

One woman doubted her husband's fidelity: "With his first wife, he had an extramarital affair, which is something I had never really worried about with us. And then all of a sudden there's no interest. He's very preoccupied, and I began to wonder." She tried to consider his perspective when managing her doubt:

> But the further on we got with the hormones, you begin to realize that he has no desire, that he's just trying to cope with the cancer, and that he's just trying to get through this period of his life, just like I am.

Several men identified that they started to feel insecure in their relationship because they were unable to sexually satisfy their partners. They reported fearing that their partner might leave them to find sexual satisfaction elsewhere.

The best strategy for dealing with doubt was to communicate with one's partner. Couples who were able to share their doubts and concerns with each other were often able to see things from a new perspective. Reassurance from their partner that they were still in love with them, and not interested in finding sexual satisfaction outside the relationship, was very important. Both patients and partners reported being reassured once they had this discussion. The challenge with communicating about doubt was facing the fears enough to actually acknowledge them to their partner: "It's the openness. Absolutely letting each other know what you're feeling, and sometimes it's a little painful. I've had some horrible thoughts, you know; not everything is always rosy."

Grief. Couples who stopped sexual activity struggled with grief over the loss of a significant part of their relationship. Couples who maintained sexual activity were also unable to avoid grief because they grieved over the way sex used to be. Some couples found that trying to have sex after ADT was too painful and emotionally distressing. For example: "I find that if we do try to become sexually active, I get very, very, very depressed. It's a reminder of what you used to have." One woman shared,

> In my experience of being a wife and a lover, I loved being able to pleasure him in that way. It's a joy, a wonderful gift. It feels like I've stopped being able to be a gift giver. I had to grieve that loss.

Grief was also expressed as frustration, as demonstrated in the following comment: "There was a time I'd have just as soon die rather than deal with all this nonsense."

Successfully coping with grief was necessary for couples to become satisfied, whether they were sexual or not. Some couples identified that they were able to do this through seeking professional counseling, whereas others indicated that what was most healing for them was to allow time to pass. Other couples were unable to articulate what they thought had helped them cope with the grieving process. Individuals who felt guilty about their sense of loss, or who failed to acknowledge their grief, had a more difficult time coping with it successfully.

Decreased self-esteem. Partners as well as patients struggled with a loss of self-esteem. For partners, prior to PCa, a salient measure of self-esteem or attractiveness was having their husband show physical attraction to them. For example, one woman reported, "It's the fact that I could walk across the room naked, which before would trigger certain things in my husband, most of them delightful to me, but it just didn't happen anymore." Another woman reported, "I don't feel the same about myself. Before, if you wear something sexy, it would turn him on. Well obviously, I can't turn him on anymore, so you feel different about yourself." Not having the visible reinforcement of their partner's erection or the indisputable interest indicated by their partner's sexual advances resulted in the women doubting their attractiveness.

For many patients, their sense of masculinity and self-esteem was also affected. The physical side effects associated with ADT changed their bodies in such a way that they no longer held the same self-perceptions about their appearance: "I guess that's something I don't think any man would want to experience. My breasts have grown. I haven't squatted to pee yet [laughs]. I'm not totally feminine yet." One patient spoke about the experience of genital atrophy:

> It's about a third the size as it was. That's gotta be the hardest part for me, to know that, you know [clears throat], I wasn't able to have sex. You just don't feel you're the man you used to be.

One patient stated, "They stole my manhood." For some men, ADT was associated with such feminizing side effects that they felt as though they were unable to fully call themselves a man. This perception changed their sense of self-esteem and confidence, and naturally flowed over into the realm of the relationship. Patients began to doubt that their partner could be attracted to and satisfied with being in a relationship with a man with a feminized body.

Two factors that contributed to coping with reduced self-esteem included a shared understanding and a sense of humor. For the partner, understanding her husband's loss of libido and learning that it did not result from her lack of attractiveness was an important realization, which required clear communication between partners. Again, the importance of understanding the intentions behind the men's behavior played a significant role in helping the women cope. This phenomenon required that partners actively seek out clarification in the case of misperceptions. They also had to make special efforts to reassure each other (as in the case of doubt). Men tended to use humor to describe the changes they had experienced to their self-esteem; therefore, laughing and making light of these changes might serve as a helpful strategy for patients.

Doubt, grief, and decreased self-esteem required that patients and their partners engage in conversation. Some couples that were unable to resolve communication issues about doubt were also unable to find solutions to struggles with grief and decreased self-esteem. This again illustrates how some solutions are likely to be successful in resolving more than one area of struggle. Furthermore, these three areas were each experienced by many couples, regardless of their sexual status. One could speculate that the very act of engaging occasionally in sexual activities might help to allay some of the concerns a partner or patient might have in these areas. Therefore, some couples might have been able to avoid certain struggles, or avoid the same severity of struggle that others experienced.

Negative attitudes toward sex. Several partners reported that a patient's "negative expectations" about the success of the sexual encounter could hinder the ability to maintain sex. For example, one partner shared,

> I think he sometimes goes in with an attitude that, "No it's not going to work," but there's other times that he does go into it—like last week, he got an erection, and I was like, "Wow!" I think that sometimes he does go in with an open mind that maybe, you know, maybe he gets wrapped up in the moment, and he starts to feel those pleasures a little bit more, and sometimes he doesn't.

It seemed that to have a successful sexual experience, it was important that the appropriate attitude be brought to the bedroom. Predicting failure resulted in failed attempts at sexual activity, whereas an open mind and a positive outlook helped prepare the way for success.

A prevalent and problematic negative attitude was that engaging in sexual activity would inevitably result in distressing emotions. Several men indicated that attempting to engage in sex was a constant reminder that they were "a failure." Many men stated that they "do not want to start something [they] can't finish." Another patient shared, "You have to learn to put it aside and go on. I find that if I do try to become, well, sexually active with her, I, you know, it's sad because you just can't get anywhere." The men consistently reported that their wives were more than supportive of any attempts to have sex, and thus their attitudes toward sexual experiences were always quite positive. In contrast, the partners reported that the men tended to endorse negative attitudes and expectancies that often predicted failure.

Couples who were able to think of their current sexual experiences as new and different, rather than trying to replicate their old experiences, were more likely to overcome this struggle. Attempting to replicate old experiences might be more often associated with thoughts of failure than creating a new experience. Thinking of their experiences as new and different allowed couples the freedom to experiment, and therefore allowed them to successfully adapt.

Discussion

ADT can have a profound effect on couples' sexual relationships (Walker & Robinson, 2010, 2011). Most couples are told before beginning ADT that they will be unable to sustain a sexual relationship (Elliot et al., 2010). Some couples struggle to remain sexually active despite relationship-altering treatment side effects such as bodily feminization and a profound loss of sexual desire. Other couples decide to stop being sexually active and subsequently struggle to adjust to a relationship without sex. Couples use a variety of different strategies to overcome the struggles. Couples often struggle for a significant amount of time before finding successful solutions to these challenges. It is our intent to provide insight into the struggles experienced by the participating couples so that their strategies of success can be offered to other couples who might find themselves experiencing similar struggles (Thorne, 2010).

The struggles involved in adapting sexually to ADT-related side effects can be conceptualized in three categories. The first category is adjusting to changes to the sexual relationship. Being open to experiencing sex in new ways and not comparing new experiences with ones from the past helped couples succeed in creating a rewarding sexual relationship. Successful couples no longer required that sex include penetrative intercourse, firm erections, or even orgasm. Several couples found erectile aids and sex toys to be helpful in restoring sexual activity. This finding is consistent with research examining the importance of maintaining flexibility when trying to accommodate sexual dysfunction in chronic illness (Barsky, Friedman, & Rosen, 2006). Barksy et al. reported that flexibility in one's definition of sex, to include forms of sexual intimacy other than penetrative intercourse, is associated with improvements in relationship quality, mood, and self-concept. Other researchers have also suggested that patients should be encouraged to develop conceptions of sexuality that do not require intact erectile functioning (Wittmann et al., 2009).

Some couples had decided to stop engaging sexually, and therefore had to adjust to the absence of a sexual relationship. These couples replaced sexual activity with other mutually enjoyable activities (Walker & Robinson, 2010). When these activities were of mutual interest, couples reported that the activities brought them closer together. Barsky et al. (2006) also reported that couples that do not maintain sex in the face of chronic illness often focus on other nonsexual interests. This strategy failed though, for couples that viewed sexual activity as essential to maintaining intimacy, and therefore as irreplaceable. Thus, these couples had to find a way to maintain sexual activity despite significant changes to their sexual relationship.

The second category of struggles, nonmutuality, related to an imbalance in experiences within the couple. A patient's tendency to withdraw from his partner was common regardless of whether couples did or did not maintain sex. The best strategy for dealing with withdrawal was prevention, which was facilitated by maintaining good communication. These couples were also less likely to report struggles in expression of affection. Open communication helped to counter misinterpretations that changes in affection meant a loss of love. Badr & Carmack-Taylor (2009) reported that maintenance of good communication is essential for successful sexual rehabilitation after PCa treatments. The authors also reported that open and constructive communication is associated with better marital adjustment. Two other helpful strategies included being physically affectionate with the understanding that such expressions are not always a prelude to sexual activity, and a concentrated effort on behalf of the patient to express affection in more pronounced ways. More explicit attempts to express affection helped partners to feel more connected, more intimate, and to feel better about their relationship. The women identified appreciating their partners' willingness to be vulnerable with them, and thus reported an increased connection.

Couples struggled with the initiation of sex because they could no longer rely on the man's libido to cue them. This phenomenon has been documented in the literature as the "myth of spontaneity" (Arrington, 2008). Three successful strategies were (a) men regularly making a point of initiating sex and being willing to engage in sex, even when not in the mood; (b) women taking responsibility for initiating sex; and (c) couples mutually agreeing to schedule times for sex. A shift in motivation for sex was observed. Patients shifted away from being motivated to engage in sex by their libido, and toward being motivated by their desire to be emotionally intimate. This is consistent with Basson's model of sexual responsiveness, which accounts for receptive sexual desire, wherein one's sexual arousal increases as one begins to participate in sexual activity, rather than requiring that sexual desire precede sexual encounters (Basson, 2005). Finding ways to ensure that both partners experienced pleasure, albeit different kinds of pleasure, was a hallmark of couples that continued to enjoy sex. Most couples decided to stop sex when pleasure was not perceived to be mutual.

The third category, attitudes and perceptions, related to individual struggles that affected the couple's sexual relationship. Most couples experienced doubt and grief. Doubt was combated through seeking reassurance from one's partner. Effective communication also facilitated the clarification of misperceptions within the couple. It has previously been documented that couples find it difficult to maintain communication about intimacy after undergoing PCa treatment (Boehmer & Clark, 2001); therefore, couples might benefit from professional counseling aimed at facilitating communication. Couples that actively processed what they lost as a result of ADT successfully grieved the loss of or changes in the quality of their sexual experiences. It has been suggested that self-disclosure of distress is not enough. Evaluating a partner's potential reaction to what one might disclose is necessary for communication to be mutually constructive, and helpful in reducing distress and fostering intimacy (Manne, Badr, Zaider, Nelson, & Kissane, 2009). Professional counseling was particularly helpful in overcoming grief and negative attitudes.

Several men reported a loss of self-esteem that seemed to stem from feeling less masculine. The women also experienced a loss of self-esteem because they feared that their partner's loss of libido was a result of their unattractiveness. D'Ardenne (2004) documented these

phenomena in an exploration of the impact of long-term illness on couple's sexuality. She also provided suggestions for how to address these issues, including referral to a marital or sex therapist. Whereas some couples in this study sought the help of professionals, others were able to overcome reductions in self-esteem through the use of humor and attempts to increase understanding of one another's perspectives through communication.

Limitations of the current study include the retrospective and cross-sectional nature of the study design. Couples were interviewed at one point in time and asked to reflect back on their specific experiences. The joint nature of the couple interviews could also present as a study weakness, because participants might have withheld information that they did not want their partner to hear (Eisikovits & Koren, 2010). Of note, we did find the participants to be extremely forthcoming, even about topics that were difficult to discuss.

Conclusion

Androgen deprivation therapy creates significant challenges for PCa patients and their partners. Couples struggle to be intimate in the face of changes in their sexual relationships and in the ways they express affection to each other. Whether couples choose to maintain sexual activity or cease engaging in sexual activity, they encounter a variety of struggles. It is inspiring to find that couples can successfully overcome the struggles involved in adjusting to life without sex, as well as to the struggles of remaining sexually active despite the man's castrate levels of testosterone. It is concerning, though, to find couples who continue to struggle and are dissatisfied with the state of their relationship. It is this group of patients who would benefit most from the help of health care professionals, and from learning about the experiences of others who have successfully overcome these struggles.

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