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Heterosexual Couples' Adjustment to Androgen Deprivation Therapy for Prostate Cancer

by

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled, "Heterosexual Couples' Adjustment to Androgen Deprivation Therapy for Prostate Cancer" submitted by Lauren M. Walker in partial fulfillment of the requirements for the degree of Master of Science.

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ABSTRACT

Androgen deprivation therapy (ADT) is considered a mainstay of treatment for men with prostate cancer (PCa), which results ADT results in castrate levels of testosterone. The effect that ADT can have on patients' intimate relationships has only recently been studied. The goal of this study was to explore how patients and their partners adjust to changes associated with ADT. Eighteen couples were interviewed. Relational adjustment and changes in sexual activity emerged as the greatest challenges for men and their partners. A grounded theory is presented about couples' adjustment process. The key findings came from this study: 1) Many couples assume sex is impossible after ADT and thus quickly accept the loss of sex, 2) Some couples struggle for years with the sexual changes or loss of sex caused by ADT, 3) Other couples are successfully able to remain sexually active despite changes in sexual function. Evidence that some couples are able to sustain satisfying sex in spite of castrate levels of testosterone is a new contribution to the literature.

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INTRODUCTION

Androgen deprivation therapy (ADT) is a common treatment for prostate cancer. Androgen deprivation can slow the progression of prostate cancer, because prostate cell growth is stimulated by androgens. The use of ADT has become increasingly common over the last 50 years (Cooperberg, Grossfeld, Lubeck, & Carrole, 2003; Perlmutter & Lepor, 2007). Patients are now starting ADT at an earlier point in their disease progression (Dacal, Sereika, & Greenspan, 2006; Giesler et al., 2005; Meng, Grossfeld, Sadetsky, Mehta, Lubeck, & Carroll, 2002; Ng, Kristjanson, & Medigovich, 2006; Smith, 2004, 2005). Rates of ADT are approximately 50% in those patients who are at high-risk of disease progression after primary treatment (Cooperberg et al.). Those who have metastatic PCa (i.e., cancer spread beyond the prostate), often receive ADT for the remainder of their lives (CCS/NCIC, 2007; Kantoff, Caroll & D'Amico, 2002). It is estimated that half a million men are undergoing ADT in North America (Barry, Delorenzo, Walker-Corkery, Lucas, & Wennberg, 2006). Further, as approximately 14% of men will be diagnosed with prostate cancer in their lifetime (CCS/NCIC, 2007) and 93% of these patients survive for more than 10 years after diagnosis (ACS, 2007), a large proportion of men and their intimate partners are impacted by PCa symptoms and androgen deprivation for a considerable amount of time.

Men undergoing ADT can experience more than twenty physiological side effects including increased risk for osteoporosis, cardiovascular disease, hypertension, obesity, anemia, diabetes type II, stroke and elevated cholesterol (Smith, 2004; Sprenkle & Fisch, 2007) as well as changes in body composition such as weight gain, decreased muscle

mass, gynecomastia (i.e. breast development), loss of body hair, experience of vasomotor (hot) flushing, and genital shrinkage (Ng et al., 2006; Templeton & Coates, 2003). Additional documented changes include emotional outbursts, increased tearfulness, increased tendency toward depression and emotional volatility, impaired memory, cognition and/or attention, dissatisfaction with body image, and distress at loss of identifiers of masculinity (Arrington, 2003; Cherrier, Aubin, & Higano, 2009; Navon & Morag, 2003; Ng et al., 2006; Oliffe, 2005; Warkentin, Gray, & Wassersug, 2006).

One groundbreaking study that focused on the sexual changes associated with ADT identified a number of challenges for patients such as erectile dysfunction, and lack of/or complete loss of sexual desire, sexual fantasies, and erotic dreams (Navon & Morag, 2003). They also found that in half of the sample, the patients' partners carried on within their marriage as if nothing had changed, while the remaining partners took control from their husbands and humiliated and rejected them. Some wives were even fearful that their husband's physical condition was contagious. Furthermore, the patients described a reduction in the capacity to feel enthusiastic about life. For example, one patient described, "Without sex, my world has grown boring, gray, mechanical…I lost the capacity to enjoy trips, music, food, even the fragrance of spring. For many months already, my whole existence lacks any enjoyment…" (Navon & Morag, 2003, p. 1384).

Most individuals on ADT have also undergone additional prostate cancer treatments such as surgery or radiotherapy. Thus, it is often assumed that the same quality of life issues associated with those treatments also apply to patients on ADT, and that care needs are universal across treatment types. Given the pervasiveness and potentially emasculating side effects of ADT, this assumption seems tenuous. Rather, it seems more

likely that men are uniquely affected by ADT, especially within the context of their intimate relationships, and that, together with their partners, they will have unique care needs.

This study sought to understand heterosexual couples' experience and process of adjustment to ADT induced changes. Patients and their partners were jointly interviewed. Three broad areas were queried: 1) Physiological changes and adaptation strategies; 2) Relational changes and adapatation strategies; 3) Suggestions for improvement for health care professionals. However, it was in the area of relational change and sexual activity that couples were most impacted, and consequently, these areas are the focus of this report[1]. The interview data was analysed using grounded theory and a model of adjustment to ADT was developed that elucidates the processes and outcomes that couples experience.

METHOD

This study was designed to assess the processes through which heterosexual couples undergo when adjusting to ADT. It was unknown, a priori, which questions would be identified as important to the study participants. Therefore, an open-ended interview format was selected in order to encourage patient-initiated discussion of topics (Stebbins, 2001). This qualitative study was implemented in order to develop a theory about the relationship between these previously unexamined concepts.

Recruitment

Upon receiving ethics approval from the Calgary Health Region Ethics Board, participants were recruited from the Outpatient Clinic at the Tom Baker Cancer Centre

(TBCC) from July to December 2008 and at the Canadian Prostate Cancer Network (CPCN) Conference, held in August, 2008 in Calgary, AB. Information about the study was distributed and phone numbers were obtained form interested participants. Study flyers were distributed through the TBCC pharmacy; however, no interested participants made contact with the study researchers via this recruitment strategy. Theoretical sampling for specific couples was obtained between December 2008 and April 2009, through referral from colleagues who were familiar with couples eligible for the study.

Informed consents were obtained and open-ended, one hour interviews were conducted with each couple. Inclusion criteria stipulated that the patient must: have been on ADT for a minimum of three months, currently have a female partner with whom they had been sexually intimate at some point, and not currently undergoing primary PCa treatment (i.e. radiation or surgery). Regarding sample size, research suggests that initial themes can become saturated at between six and nine interviews (Guest, Bunce & Johnson, 2006), while Creswell (1998) recommends collecting between 15 and 20 data sources. Therefore it was estimated that between 12 and 15 couples would need to be interviewed. After the initial interviews, theoretical sampling was utilized to ensure saturation, resulting in a total of 18 interviewed couples.

Three specific interview questions were utilized in order to guide the participants: (1) "What kinds of changes did you notice after beginning ADT, and how did you adjust to these changes?",(2) "Did you notice any changes that affected your relationship, and how did you adjust to these changes?" and (3) "What advice would you give to future patients or health care professionals regarding the administration of ADT?" Couples were

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[1] An overwhelming majority of the content that surfaced in the interviews related to relational changes,

encouraged to explore any areas that they felt were relevant to their experience on ADT, and were instructed to speak openly and honestly about the nature of their experiences.

Analysis

Interviews were digitally audio-recorded and transcribed verbatim. Following transcription, a well-established and rigorous qualitative technique known as grounded theory was utilized to extract themes that emerged in the dialogue (Strauss & Corbin, 1998). The emerging concepts were coded using NVivo 8 software (QSR International, 2009) and initial codes are included in Appendix A. The relationships between emerging concepts were organized into a theory that was based directly on the data. The aim of the grounded theory analysis is not to obtain a typical or broadly representative set of findings, but rather a set of theoretical propositions about the data and an integrative theory about the relationships between emerging concepts (Glaser, 1998). In order to increase confidence in the validity of our findings, a summary of the ascertained themes was provided to participants who were then given the opportunity to review and make comments prior to the composition of the research conclusion. (Further details about the method selection, analytical process, and coding procedure, are included in Appendix A).

Participants' names and potentially identifying information was eliminated from the interview transcripts. Study documents are available only to the primary investigators and are to be destroyed seven years after study completion. Selected quotes included in this report have been edited for readability and to protect confidentiality (Morse, 2007).

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rather than the other queried areas.

RESULTS

Sample Demographics

A total of 18 heterosexual couples were interviewed. Patients ranged in age from 47 to 83 years with a mean age of 65.4 years. Female partners ranged in age from 32 to 82 years, with a mean age of 61 years. Sixteen couples were married (duration ranged from 1 month to 60 years), and two were dating (duration ranged from 1 to 5 years). The total average duration of relationship for the whole sample was 33 years. Length of time since diagnosis ranged from 8 months to 15 years and duration of ADT ranged from 4 months to 13 years.

The total number of couples who remained sexual at the time of the interview was 9, whereas the remaining 9 couples had stopped having sex. Two couples were not sexually active prior to undergoing ADT. Thirteen couples were identified as satisfied, (although 7 of them went through a struggle before eventually reaching a satisfied outcome) and 5 couples were dissatisfied at the time of the interview. Eight couples had sought some type of counselling before the time of the interview though this was evenly divided across group status (2 among the acceptance/satisfied group, 3 among those who had struggle/satisfied group and 3 among the struggle/dissatisfied group).

The Grounded Theory

A grounded theory was developed about the process of relational adjustment for couples affected by ADT. Figure 1 presents a visual representation of this theory. There were three possible outcomes for couple's relationships following administration of ADT. The first outcome identified couples who were able to quickly adjust to the changes brought by ADT. These couples became satisfied and accepted an intimate

relationship without sex. In many cases, "satisfaction" was self-identified by participants. Satisfaction meant that couples were content with their current state, and were no longer struggling or striving for improvement. The satisfied state appeared to be relatively stable (i.e. once it was achieved, it was less likely to fluctuate than the dissatisfied state). Furthermore, "non-sexual" within the context of the interview referred to engaging in no sexually intimate contact (including coital sex or intercourse as well as activities typically thought of as foreplay); these couples belonged to the 'stop sex' category. This did not mean that these couples did not value sex, rather it indicated that at the time of the interview they were able to accept a relationship without sex. It has been assumed in oncology practice that ADT couples must give up sex in exchange for a life sustaining cancer treatment. The results of this study have provided support for the accuracy of this assumption in some cases. For example, one couple whom had previously enjoyed a very rich sexual life, found they were able to accept the loss of sex due to ADT because they were focused on his survival. Another couple identified that they were able to accept a life without sex because they had come to the conclusion that was impossible to maintain sex and therefore they assumed they had no other option but to accept the change to their relationship.

This study revealed that there are two other possible outcomes for couples which do not involve the same acceptance process found in the aforementioned group. These two groups included couples who struggled and remained dissatisfied, and those who struggled and became satisfied. Couples in these two outcomes would have made a decision either stop or maintain sex. Though prior to ADT, the word sex may have been equated with penetrative intercourse, for those who remained sexual after ADT, the

definition of sex was renegotiated to include all activities considered sexually intimate (including intercourse, being naked together, sexual touching, and caressing). Couples who were unable to resolve their conflict or struggle remained in a state of dissatisfaction. In couples who struggled and were clearly distressed, dissatisfaction was very evident. These couples were also found to be in want of, or striving for, a positive change. For example, over the course of 13 years, one couple struggled with maintaining sex in their relationship. They found that the quality of intercourse had changed so much that whenever they engaged in sex, they were reminded of the loss they had experienced. However, while the patient and his partner became depressed or sad during sexual encounters, they still did not give up on sex. Although this couple continued to engage sexually, they remained dissatisfied due to the sadness and/or guilt associated with engaging in sexual activity of diminished quality. Another couple who remained dissatisfied, had decided to stop sex felt disconnected as a result of struggling with feelings of grief and had withdrawn from each other at the time of the interview.

The third outcome for couples involved the same struggle process as the dissatisfied couples, however, these couples were able to overcome their struggles, and to reach a state of satisfaction. These couples may have made a decision either to stop or to maintain sex, each of which posed unique struggles. The most important feature of this group is that despite experiencing a struggle, these couples were able to find satisfaction For example, one couple made many efforts to maintain sex because they felt that intercourse was too important in their relationship to abandon. While it was a difficult process, they found sexual experiences, though different than before ADT, to be very fulfilling for each of them. Another couple that had decided to stop sex, struggled for a

period of time with managing issues like how to replace the lost intimacy in their relationship and how to show affection to each other; however, over time they were able to resolve these issues and came to identify themselves as satisfied.

Within Figure 1, arrows (drawn from the right side of the model to the left side) indicate that a couples' status or outcome must have been continually reinforced during the re-evaluation process. However, couples could come to a new decision at any time, changing their subsequent reaction and outcome. Specific characteristics were associated with each of the three outcomes, regarding the way in which the couple adapted to their new outcome, and the way in which the couple came to a conclusion about whether to maintain or stop sex. These different characteristics were most apparent in the evaluation/re-evaluation process (where decisions were made).. As shown in Figure 1, the process of adjustment is fluid and changing. For example, some couples reported that when something disrupted their state of satisfaction, they found themselves embarking on a new process of adjustment, and sometimes a new decision about maintaining or discontinuing a sexual relationship..

Characteristics of the Acceptance and Satisfied Group

Evaluation and Re-evaluation: Explicit Discussions about Sex

Most of the couples in the acceptance/satisfied group mentioned that they did not have a conversation about the changes that had occurred within their sexual relationship. For some couples, avoiding the discussion was an intentional attempt to avoid the emotions and pain that would surface. For instance, one woman stated, "I never bring it up because I know he can't help it. There's nothing he can do about it." Therefore, in order to remain in a satisfied state, these couples did not venture into conversations that

could be considered painful or uncomfortable. Likewise, one patient reported, "Oh, I think anybody misses [sex] periodically. It's not something that we got angry about, or talked about, we were fine with it." These couples are able to bypass the challenging topics that are often difficult for other couples to discuss, and seem to shift their focus to other important areas in their lives, such as advocacy and support. For these couples maintaining sex is no longer a priority.

As these couples did not explicitly discuss sex, it is also possible that a couple could think the issue was not important and thus not worth discussing. Couples in the acceptance/satisfied group most often reported that they "were fine with it [stopping sex]". For example, one patient reported, "I don't think we had many discussions about it, we just sort of mutually didn't make much effort on it." One partner shared, "I don't think we really discussed it. I just think it was a matter of course he couldn't, once he had taken up with his treatment. But we never really gave it a thought." Interestingly, all of the couples who refrained from discussing the topic with each other were identified in the acceptance/satisfied group.

Evaluation and Re-evaluation: Dichotomous Thinking

Dichotomous thinking appears to catapult the couple past the decision making process about maintaining or stopping sex. For these couples, it is as if the decision to cease sex had already been made, and because it is never considered a possibility, couples adapt to life without sex relatively quickly. Interestingly, these couples all identified themselves as being satisfied without having sex. All individuals who subscribed to this outcome endorsed the following two types of dichotomous thinking:

1. Focus on Survival. A reoccurring theme expressed by the women in this group was that they would rather have their partner alive than keep sexual activity a part of their lives. This statement or some variation was made in all of the cases in the acceptance/satisfied group. Examples include, "As far as I'm concerned anything that prolongs his life is worth it"; "To have him alive, that's more important than the sex"; "It was a no brainer, I'll pick having him around longer, than, having sex." This dichotomous thinking rests atop the assumption that a person can experience only one of two outcomes: either she accepts her partner's imminent death in order to maintain sex, or she relinquishes sex entirely, in exchange for her partner's life. One partner illustrated this dichotomy precisely when she stated, "You can't make love when you're dead". She indicated that she had not considered maintaining sex because doing so would have required her partner to reject a life prolonging treatment. Over half the entire sample acknowledged a focus on survival, however, couples who were not in the acceptance/satisfied group did not subscribe to the same dichotomous thinking that followed, and indicated that they could sustain both survival and sex.

2. Can't Do Anything About It. The second type of dichotomous thinking also occurred in the acceptance/satisfied group. These couples indicated that attempts to have sex were hopeless and frequently reported that 'there is nothing that can be done'. For example, one partner reported that although she was still frequently interested in having sex, she was waiting until her desire dissipated with age so that she would not have to think about it anymore. She actively ignored any moments of sexual desire or arousal and reported that she avoided discussing the topic with her partner because "...he can't help it. There's nothing he can do about it." Another couple reported, "We just accepted it and

have gone on. There's no point in dwelling on it, if it's not gonna work, it's not gonna work." Yet another couple stated, "It's really hard to come to terms [with] it. I really don't think there is any way, it's just something that's gone, that's impossible, and there's no way to fix it. Just accept it and put up with it." Therefore, it is possible that this dichotomous thinking served as a coping mechanism for this group of patients, allowing them to bypass making a decision about sex and to make the best of their situation by learning to accept a relationship without sexual activity.

Evaluation and Re-evaluation: Knowledge about Side Effects

Intuitively, it would seem that if couples were informed that it is possible to maintain sex after ADT, they would be more motivated to do so. The corollary of this is that if couples were told that having a sexual relationship would no longer be possible, they may immediately give up on the idea of maintaining sex. This was the case for many couples in the acceptance/satisfied group. For example, one partner determined that sex would be impossible because her physician had told her that "there probably wouldn't be the possibility of having intercourse and that it was unlikely that he would be able to ever again". This partner was unable to see the possibility within the physician's words, 'probably' and 'unlikely'. Furthermore, she assumed that ending 'intercourse' also meant ending all sexual experiences. Therefore, this couples' dichotomous thinking pattern influenced their interpretation of information about ADT related side effects.

Evaluation and Re-evaluation: Reasons to Discontinue or Maintain Sexual Experiences

While the process of evaluating the reasons for and against maintaining sex was important for other couples, it did not surface as an important issue for the

accepted/satisfied group. Perhaps this is because these couples spent very little time in the active decision making phase, as maintaining sex was assumed to be impossible.

Reaction to Loss of Libido and Termination of Sexual Experiences

Many patients identified that they were able to come to terms with the loss of sex and move on. While some individuals struggled with these changes, those in the acceptance/satisfied group were able to quickly accept their new situation. One man reported, "I'm fine with it, to me it's not a priority in my life now…it isn't necessarily high on the list. Yes, it's nice to have but it's not a must have, it might be a want, not a need." Another man described indifference toward this change, "Once the hormones kicked in it didn't bother me. I really didn't think about it, to be honest. I just couldn't be bothered with it." Some men indicated that their sexual frequency was already decreasing prior to ADT, and had expected it to eventually become non-existent, "I mean when you get older anyways, the sex, the sex aspect of marriage is deteriorating actually. I think it's different from when you're younger."

Partners in the acceptance/satisfied group were also able to accept that their relationships no longer included sex. Examples of this finding include: "I don't really have much of a problem with it"; "It [sex] wasn't the only thing that we had in common, let's put it that way. We're really good friends and we have a lot more going for us than sex", and "It's nice to be hugged, but as far as being fondled or getting into a position where you would feel like you want sex…I guess we're sort of ho-hum." Therefore, the women were able to put sex aside and focus on other areas regardless of whether sex was or was not important to them in the past.

Two partners reported their appreciation of the changes that decreased libido and sexual activity brought to their relationship. "To me it's a big relief because I've never had a hugely powerful sex drive at all whereas he did. So, the fact that he was less demanding now was actually quite a relief (laughs)." In this case, stopping sex may have led to a decrease in relational tension because the couple's interest in sex became more balanced. This experience of relief over the cessation of sex was most common in the acceptance/satisfied group.

Characteristics of the Struggle (Dissatisfied and Satisfied Groups)

Evaluation and Re-evaluation: Explicit Discussion about Sex

Most couples in the struggle/satisfied group specifically mentioned having intentional conversations about the challenges that ADT posed to their sexual relationship. For couples who regularly engaged in open discussion throughout the marriage, direct communication about the nature of their sexual experiences was consistent with their normative route to marital problem solving. Honest communication seemed to help couples increase clarity about each other's expectations allowing them to avoid making inaccurate assumptions. Constructive communication in these couples helped aid in perspective taking, setting realistic expectations, and establishing priorities. Communication also allowed couples to help each other work through anger, stress and anxiety, to increase understanding and sensitivity to each other's feelings, to discuss insecurities, to remind each other to stay positive, and to facilitate both active problem solving and planning ahead. Open and honest communication allowed for facilitation of these key areas which reportedly aided in the maintenance of sex. Working through grief

over the loss of sex and determining how to establish intimacy and connection in the midst of changes in the sexual relationship were important to those who had stopped sex.

Couples who communicated about the changes to their sexual relationship appeared to be both more likely to be couples who decided to maintain sex, and more likely to be successful at overcoming struggles. Though the struggle may have been a long process, most of these couples seem to find satisfaction. Therefore, communication seemed to facilitate successful transition to the struggle/satisfied group. For example,

> It wasn't easy to talk about. Sexuality. We fumbled about before we eventually got it out on the table. He worried that he wouldn't be able to finish what he started, but I needed to be cuddled and held. It wasn't the finishing that I was worried about. We try to be patient and understanding with each other. I still think that we have a sex life. It's very intimate. I don't think we are lacking anything, except intercourse, but we are still very satisfied.

One couple in the struggle/dissatisfied group, reported that they felt no need to discuss issues of sexuality. Paradoxically, they indicated that, "it would certainly be better being open and discuss it more for most couples I think, but we, we didn't really talk about it an awful lot."

Evaluation and Re-evaluation: Dichotomous thinking

Over half of the entire sample (11/18) acknowledged that they were focused on the patients' survival, however, couples in both the struggle/satisfied and the struggle/ dissatisfied groups did not subscribe to the dichotomy present in the acceptance/satisfied group. Those couples who were able to maintain sex, reported thinking that both outcomes (i.e. sex and prolonged life) could be maintained. Some partners stated that though they were focused on the survival of the patient, they were torn and often felt guilty because they still considered sex to be an important part of their relationship. Other couples struggled to adjust to a relationship that did not include sex.

Evaluation and Re-evaluation: Knowledge about Side Effects

There appeared to be no differences in previous knowledge about side effects between the struggle/dissatisfied group and the struggle/satisfied group. Often, individuals who had struggled complained that they were not adequately prepared for the side effects of ADT, or that they had been unable to comprehend the information or medical literature that had been given to them before commencing ADT. Some couples also expressed that although they had been informed about the side effects, they assumed at the time that they would not experience those side effects. Other patients explained that though they were informed about the side effects, they did not understand how they would be affected by them until they had begun to experience the side effects for themselves.

Evaluation and Re-evaluation: Reasons to Discontinue or Maintain Sexual Experiences

Couples who struggled (whether satisfied or dissatisfied), spent more time making a decision about whether or not to maintain sex, than couples in the acceptance/satisfied group who immediately accepted a non-sexual relationship. Evaluation of the reasons to maintain or discontinue sex was an important process for those in both the struggle/satisfied group and the struggle/dissatisfied group.

Reasons to maintain sexual experiences included that it was important to either or both partners, helped to maintain intimacy, brought enjoyment, provided a necessary release, had improved since ADT, and made up for other faults in the relationship. Reasons to discontinue sexual experiences included non-mutual (i.e. unbalanced or non-reciprocal) experience of libido, non-mutual pleasure, non-mutual effort, or non-mutual willingness to participate in sex. Other reasons to stop sex were that it was no longer a

priority and that maintaining non-penetrative or non-spontaneous sex was too emotionally painful. Therefore, the couple's previous experience with sex and values associated with sex may have also played a role in their decision to maintain or stop sex. A detailed description of these reasons is included in Appendix C.

Reaction to Loss of Libido and Termination of Sexual Experiences

While initially adjusting to the loss of one's libido can be difficult, most of the men in the struggle/satisfied group tended to reach a point at which they became indifferent about their loss of libido. Furthermore, they often identified that their ability was seen as a "bonus" if they were able to engage in sexual activities despite a low libido. The adaptation to one's loss of libido seemed to be a process where one's initial reaction could range from anger and frustration, to disappointment or depression, and eventually to a state of indifference or tolerance. The partners had similarly varied responses to the loss of their spouse or partner's libido and sexuality.

Some couples reacted to stopping sex by stating that it was not the best choice for them. One couple, who had stopped being sexual prior to ADT, shifted and decided to maintain sex. While the originally were identified as part of the acceptance/satisfied group, they transferred to the struggle/satisfied group. Though struggled with some aspects of this shift in outcome, the partner reported advantages associated with this change:

> The imbalance was before, where he was always more active than I was, so he'd be ready, he'd be aroused, he'd want to have sex, and well, for me, sometimes it didn't matter. He'd have to arouse me to get me into his mood. But now we, we seem to be at the same level.

Another couple initially accepted a non-sexual relationship because they assumed it was impossible to engage sexually after ADT. At a later point however, they decided to

attempt a sexual experience and found it to be enjoyable. These examples illustrate how couples can shift from the acceptance/satisfied group to the struggle/satisfied group.

Interestingly, couples could also be of different opinions, where sex was still important to one partner but not the other. For example, when one couple was asked how they had adjusted to not having sex in their relationship, he responded, "At the beginning, it killed me", describing how the process made him feel like "less of a man". In contrast, she laughed and described his loss of libido as "a little mole hill in your relationship that you [have] got to let go". This imbalance of opinion and priority was present in the struggle/dissatisfied group, where disagreement often reflected dissatisfaction.

For patients in both the struggle/dissatisfied and struggle/satisfied groups, the process of adjusting to a loss of libido and reduction or termination of sexual experiences was a significant challenge. These patients reported comments like the following: "Not being able to perform in the bedroom, it's just, it's demoralizing"; "They stole my manhood"; "There was a time I'd have just as soon die rather than deal with all this nonsense"; and "It was just very depressing and it still is, this is the biggest let down for me, sometimes I just can barely cope with it." Furthermore, one man described how the loss of sex within the relationship created other complications for him and his wife, "Not having a good sex life really made me withdraw, I wasn't even going to touch her because she would think I would be interested when I'm really not, and then she might get all hot and bothered and I'm not..."

For those women who still had a libido and who were still interested in maintaining a sexually intimate connection with their partner, the process of adjusting to their partner's loss of libido was reportedly very difficult. This is the case for both couples

who maintained sex and those who did not. For example, one partner described her fears about the relationship, "I was very afraid of becoming, umm, living together like a brother and sister. It feels like you're going to move into this platonic sort of relationship where there's none of that wonderful thing that you had as a husband and wife." Another woman shared her loss, "It's been frustrating because I almost feel like I'm losing my partner. I'm losing my best friend." Another woman spent a great deal of time grieving the loss of her sexual relationship, "I think he grieved the loss of what had been, and he certainly grieved for me in the midst of my grief, because it was profound. I'd say we've probably spent the last three years working seriously through that.' She also reported the presence of guilt, "I felt guilty, people would say 'well you've got your husband, these things aren't important, just put that aside don't worry about it anymore'. Well, unfortunately or fortunately I still had all the feelings, I still had the libido". Still another woman reported on how she was waiting for her libido to decrease, "(sighs) I'm getting older, (laughs) I'm in my seventies, so I suppose that maybe it will just go away one day (laughs)."

A smaller subset of struggling women indicated that they spent time worrying about what their spouse was thinking about their sexual experiences. These women were unsure how to interpret their partner's lack of sexual interest, and unsure of how to navigate a new relationship that existed without, or with fewer, sexual experiences. One woman shared what it was like to adjust to not having sex anymore, "It was so foreign to us. We both had enjoyed our sex life. I didn't know how to tell him that it was OK. I worried about making him feel like it never was important to me." She described how challenging

it was playing guessing games about what one another were thinking and she was unable to reach an understanding until they talked about these changes candidly.

While some partners in the struggle/satisfied group actually identified that they appreciated the decrease in tension that resulted from no longer having unbalanced levels of sexual desire, other women reacted with disappointment and grief. This reaction may be due to their desire to have sex with a partner who was no longer sexually interested. For other women, it was a constant struggle as they continued to engage sexually despite their partner's loss of libido and increasing erectile dysfunction. Some patients wanted to engage in sexual activities for the benefit of their wives and were able to do so, while others struggled to cope with the reduction in the quality of the sexual experience. Both patients and partners identified that they needed to grieve this loss of quality (e.g., they could no longer receive the same pleasure that they used to from sex). The partners' responses were as varied as the patients' responses, however, the= partners' responses appeared to be more stable and rarely transferred from a negative state to one of indifference, as did the patients'. Those in the struggle/satisfied group described learning not to focus on the negative feelings they previously had, and to begin to look for the positives in the relationship, whether or the relationship included sexual experiences or not.

Areas of Struggle

The following areas were identified as areas of struggle: Absence of Sex, Unwanted Sexual Desire, Patient Withdrawal, Expressing Affection, Doubt, Grief, Decreased Self-Esteem, Negative Attitudes, Changes to Sex, and Unbalanced Initiation and Effort. At any given moment these issues may have been relevant or irrelevant to couples, therefore

movement through these categories is quite variable. Not all couples experience each of these struggles. Overcoming these struggles, regardless of whether the couple stopped or maintained sex, is what appeared to transition a couple from a dissatisfied to a satisfied state (this tendency is indicated by the arrows in Figure 1).

The areas of struggle were also divided into three categories, those that were associated with the maintenance of the 'stop sex' status and those that contributed to the 'maintain sex' status (and those that were associated with both; i.e., affection, grief and self-esteem). In some cases, overcoming one struggle can also impact other areas of struggle. Furthermore, there was relationship between the struggle and the Evaluation/-Re-evaluation process (as indicated by the arrow in Figure 1), demonstrating that during a time of struggle the couple may have began to re-evaluate their decision to maintain or to stop sex.

Struggles Associated with Decision to Stop Sex[2]

Absence of Sex

Couples who were able to find satisfaction without maintaining sex were often able to deal with the absence of sex activity by replacing it with some other valued activity. For example,

> 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.

Replacing sex seemed to be a common coping mechanism that, though challenging, allowed couples to move on after eliminating sexual experiences from their relationship.

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[2] These factors are also relevant to the acceptance/satisfied group (Figure 1), however they do not surface as areas of struggle but areas in which the couple seems to readily adapt to.

Unwanted Sexual Desire

Though sometimes jokingly, couples who were no longer sexual described how challenging it was to ignore or disregard unwanted sexual desire or arousal, because it would never culminate in a sexual experience. This was particularly important for partners whose libidos remained intact. Often the partners described "working" and distracting themselves with a "cold shower." Other partners described drawing a line when it came to sexual thoughts, "I have a mental block, I just know that it won't work, and I can't have that." This patient shared, "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 with her, it's, it's sad because you just, you can't get anywhere." If couples were successful at 'putting sexual thoughts aside', then they would get to an end point described by this patient, "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". Avoidance and distraction were used to help the couple disregard sexual desire. Furthermore, after making the decision to cease being sexual, over time, the desires dissipated.

Patient Withdrawal

One of the phenomena that complicate couples' adjustment is the patient's tendency to withdraw, leaving his partner feeling isolated. 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 all together. 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.

In order to avoid isolation, the women tended to facilitate conversation and were particularly persistent in making a conscious effort to engage him in conversation, "[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?'." She spent time probing for what may have been concerning him, and made an effort to understand and recognize how various stresses were impacting him. Perspective taking became an important part of the communicative process. Interestingly, many men indicated that when they reciprocated in the conversation, they often felt better about 'getting it off their chest'. It is possible that discussion is initiated because the women feel they are lacking intimacy, or because they see conversation as a way to grieve. Another possible explanation is that communication fills 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 though it was challenging, they maintained communication. They further specified that, though the loss of sex and their adjustment to ADT were not pleasant to talk about, they discussed it anyway. Interestingly, those couples who communicated openly were more likely to be those who were successful at establishing affection. Therefore, some of these areas of struggle are related to each other and resolving one (e.g. withdrawal) may help lead to a solution in another (e.g. affection).

Struggles Relevant to both Stopping and Maintaining Sex

Expressing Affection

The only couples to actually make a change in the way they expressed affection toward each other were those who were intentional about communicating. The following patient exemplar illustrates the challenge to intimacy that stopping sex can bring upon a relationship,

> You can't get, physically active sexually so that definitely has to affect your closeness, in that respect, but I know there are different ways of being close other than sex, but to both of us, the sex was a big part of our life. That real closeness in sexual activity, that part is gone so you know it has to affect your relationship, there's just no two ways about it.

Challenges in expressing affection appeared to affect the partner more than the patient. One partner was distressed by the fact that her husband rarely made an effort to express affection, and reported that without intercourse, she began to doubt his feelings for her. She described the things that she would appreciate him doing in order to show her affection, such as preparing dinner for her or bringing home flowers. She was most concerned that, "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."

However, not all couples felt as though ceasing intercourse also required ceasing affection. For example, one woman feared that with the 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." Another 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." Therefore, he was able to maintain physically intimate activities without

requiring that they lead or progress on toward a sexual encounter. Another patient described how by talking to other female partners of men on ADT, he learned to be more affectionate and to use less subtle techniques in order to show his affection to his wife, "I'm more flirtatious now with her than I was before [ADT], but she is a lot more understanding too, so it makes it easier."

In fact, a few couples indicated that there have been some advantages that 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 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 more of a 'taking in' of the love that I think I've always expressed and to my touch. He's very responsive, more responsive than, than he's probably ever been in all of these years.

Doubt

Without a clear indicator of whether her partner still loved and was attracted to her (i.e. sexual arousal), this woman recalled the doubt she felt about his feelings for her, "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." Some men doubted that they were able to satisfy their partners and though they were reassured by their partners, they still identified fleeting thoughts that their partner may leave them. Another woman shared her experience doubting whether or not her husband was being faithful to her, and the role of communication and perspective taking in managing this doubt.

> With his first wife, he, 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. 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.

Grief

Those couples who stopped sex struggled with grief over the loss of a significant part of their relationship. Those couples who maintained sex grieved over the changes to their sexual experiences. Some of the participants also indicated that their current attempts at sexual experiences simply reminded them that they were failing sexually. Others felt that the changes to their sexual relationship were so drastic that they needed time to grieve their losses. This 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 by the patients, 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." Grief may also have been expressed as frustration as was demonstrated in the aforementioned quote, "There was a time I'd have just as soon die rather than deal with all this nonsense."

Those couples who maintained sex and those who were able to become satisfied (whether sexual or not), had to overcome feelings of grief. Some couples identified that they were able to do this through counselling, while others identified that allowing time to pass had been healing. Other couples were unable to articulate what they thought had helped them in the healing process.

Struggles Associated with Maintaining Sex

Decreased Self-Esteem

Related to the patients' loss of libido, at least half of the partners acknowledged that their self-esteem had been affected negatively. For example, one woman says, "I think that 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 identified the embarrassment and emotional pain she experienced as a result of doubting that her partner still found her attractive, "Now when I want it [sex], it's almost like I have to ask him or beg him. It's hurtful because then I don't feel attractive or I don't think that he finds me attractive. It's hard." 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".

For some patients, their sense of masculinity and self-esteem was also affected, "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." While this patient shared about the experience of genital shrinkage, "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. As previously mentioned, one patient described, "They stole my manhood."

Two factors which contributed to increasing self-esteem included understanding and humor. Understanding her husband's loss of libido and learning that it did not result from her lack of attractiveness required clear communication between partners. Men tended to use humor to describe the changes they had experienced to their self-esteem.

Therefore laughing about these changes may serve as a coping mechanism for patients. For some couples successfully managing and/or struggling with self-esteem were ongoing processes that would fluctuate in importance over the years.

Negative Attitudes

Several partners reported that negative attitudes hindered the ability to maintain sex,

> I think he sometimes, he does go 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 in order to have a successful sexual experience, it was important that the appropriate attitude be brought to the bedroom.

Changes to Sex

Some couples illustrated how they were able to adapt or renegotiate their sexual relationship and experience intimacy in a new way. For example, "We like having nice dinners, we like having a nice bottle of wine, we like going out, having a game of golf. I still like to somehow get involved, sexually involved even though it doesn't involve intercourse." Couples also had to learn how to adapt sex because of constraints and challenges associated with ADT. Often this process included changing the goal of the sexual encounter from orgasm to enjoyment.

> 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. And 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.

Another couple described replacing sexual acts with physical and sensual acts, and started sharing sensual massages. She described, "I would say that the massage itself can

be as much, or more sexual, and 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."

Almost half of couples volunteered information about using or attempting to use oral erectile medications, erectile aids, or toys to restore sexual activities. While not all reviews were overwhelmingly positive, these methods were still appreciated by many. This patient reported his success with injections,

> 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.

Another woman described what it had been like to use dildos in sex play 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." Though the sexual experience is different in terms of objects or aids, a key to success was that it remained mutual. Another key factor was having a good sense of humor, "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".

Unbalanced Initiation and Effort

One partner reported how her husband could no longer rely on his spontaneous sexual desire to motivate a sexual encounter, "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." Therefore, successfully maintaining sex was associated with a shift in 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 a richness to our intimacy and allowed him off the hook to start what he has no inclination for."

Another way to prevent an imbalance in initiation was to schedule a specific time for sexual encounters. The following 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 with a lowered libido who were still sexually active 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. Furthermore, the partners frequently reported that when sexual activities focused specifically on her pleasure, she would feel guilty because he was not enjoying it as much as she was. It was important that couples directly communicate about these issues in order to reach a conclusion that satisfied both partners.

Additional Coping Methods

It was necessary for couples to overcome their struggles in order for them to achieve a struggle/satisfied outcome. Each struggle experienced by the study participants was uniquely complex in its own right, however coping mechanisms and strategies were often related. Many couples indicated that they were able to develop an appreciation for each other and what they can share together as a couple. Identifying themselves as best friends and becoming closer with each other, also seemed to play a key role in successful maintenance of intimacy. Many couples indicated that they had known each other a long time and loved each other very much and that these factors were important to their success. Sharing common interests seemed to be an asset to helping couples adjust to no

longer being able to share sexual experiences.

Other strategies included developing a sense of empathy and understanding of each other. For a few participants, developing separate interests and enjoying time apart was a key to their successful adaptation. Other couples identified that over the years they had learned to 'fight well' or to fight fairly. These couples were able to work through challenges and differences without permanent damage to the relationship. Other couples identified that laughter and humor had helped them adapt to the changes that ADT had brought to their relationship. Being able to motivate each other seemed to be a key strategy for some couples. Furthermore, couples who identified themselves as a team also seemed to adapt successfully. Trust and respect for each other appeared to be a strong development within the relationship. In addition, being willing to make sacrifices for each other appeared to make a difference in terms of adapting to the significant changes that ADT played in terms of sexual experiences. Willingness to be flexible and open-minded also was a determinate of success. Additional strategies included clear communication, perspective taking to increase understanding and maintaining positivity, having realistic expectations and seeing sexual activity as a "bonus".

DISCUSSION

The aim of this study was to assess the process of adjustment that couples experience while patients are undergoing ADT. To date, there has been only one study examining the impact of ADT on intimate heterosexual relationships (Navon & Morag, 2003). The grounded theory produced in this study has the potential to increase understanding of the adjustment process associated with ADT, as well as to guide interventions and programs that may assist couples to adapt to this challenging process.

The Grounded Theory

After ADT was administered, couples determined whether sex was an important part of their relationship that was worth maintaining. Although most couples identified that sex was an important part of their relationship at some point in time, many couples decided to stop sex. For some couples acceptance and satisfaction quickly followed this decision. This finding is consistent with the assumption that couples will easily adjust to ADT induced sexual changes because the man no longer has the desire for sex (Dahn et al., 2004). Furthermore, this also rests on the assumption that sex is impossible with castrate levels of testosterone (Allen, 1962; Warkentin, Gray & Wassersug, 2006; Wassersug, 2009).

Conversely many couples were dissatisfied with the loss of sex in their relationships and therefore decided to maintain sex. Such a decision was inevitably followed by a period of struggle. However, whether their decision is to stop or maintain sex, most couples experienced many struggles including: Absence of Sex, Unwanted Sexual Desire, Patient Withdrawal, Expressing Affection, Doubt, Grief, Decreased Self-Esteem, Negative Attitudes, Changes to Sex, and Unbalanced Initiation and Effort. Some couples were unable to overcome these challenges and remained dissatisfied for a considerable period of time. Importantly, however, this study reveals that some couples are able to adapt and find a way to remain sexually satisfied. It has been previously assumed that this outcome was not possible (Allen, 1962; Warkentin et al. 2006; Wassersug, 2009).

Lastly, the theory represents the idea that couples can transition through various outcomes. For example, a couple could shift from the struggle/dissatisfied group to the

struggle/satisfied group and then may find that a new struggle emerges. In some case, couples reported that after being dissatisfied for a while, they re-evaluated their decision to either maintain sex or stop sex and then chose the other option. It is also possible for couples who initially accepted a relationship without sex to experience some change in the relationship that leads them to attempt to maintain sex. Furthermore, the grounded theory alludes to the nature of the struggles that couples contend with while on ADT, as well indicates possible coping methods.

Clinical Implications

Disseminating the results of this study will increase awareness of the importance of the sexual relationship for many couples coping with ADT. Hawkins et al. (2009), suggest that health care professionals need to provide "permission" to couples not only to discuss sexuality but to engage in sexual intimacy in the midst of cancer, by "legitimating discussion" (p. 8). Increased understanding and legitimization of couples' concerns regarding sex is essential, as couples often reported feeling guilty about caring about sexuality in the midst of battling a life threatening illness (consistent with d'Ardenne, 2004).

Interestingly, most of the couples in the acceptance/satisfied group, reported that they were not aware of the possibility that they could have chosen to maintain sexual activities. These couples endorsed dichotomous thinking such as, assuming that in order to maintain life, sex had to be sacrificed (also found in Hawkins et al., 2009) and assuming there were no possible solutions to allow for the maintenance of sex (consistent with Gilbert, Ussher, & Hawkins, 2009). Given that many couples were not informed about the possibility of maintaining sex after ADT, an ethical issue arises for therapists. If

a couple assumes that they cannot be sexual, and reaches the acceptance/satisfied state, a therapist could inform the couple of the possibility of becoming sexual, supporting early intervention. The results of this study could be shared with patients to help them prepare for what may occur in their adjustment process. Alternatively, it could be detrimental for a therapist to suggest that couples reconsider their decision to stop sex, leading the couples toward the struggle process. Unassisted, the couples could remain in that struggle indefinitely. Because couples can shift their position in the model at any time, it is important for therapists to consider the impact that their decision to intervene may have on a couple's adjustment. Additionally, couples need to be informed before commencing treatment, that maintenance of sex is a possibility after ADT. They should also be informed that couples who maintain sex, struggle through various challenges and may benefit from professional counseling. For not all couples are these struggles necessary or warranted in order to achieve successful adaptation to ADT, as some couples are satisfied without maintaining sex.

Informing patients about the possibility for maintenance of sex would allow for couples to experience the benefits of a sexual relationship. Sexual satisfaction has been shown to be related to increased quality of marital relationships, increased marital stability (Yeh, Lorenz, Wickrama, Conger, & Elder, 2006) and to have a significant influence on self esteem and marital satisfaction (Boehmer & Babayan, 2004). Relationship quality has also been evidenced as a significant predictor of overall quality of life in non-androgen deprived PCa patients, while one of the most significant predictors of quality of life for female partners, is sexuality (Perez, Skinner & Meyerowitz, 2006). As maintenance of sexual intimacy acts as a buffer against the

negative effects associated with declines in health, marital satisfaction and marital quality (Harper, Schaalje, & Sandberg, 2000), it is possible that maintenance of sex could also serve to improve overall quality of life in those couples affected by ADT.

It was observed that couples who were willing to renegotiate or to adapt their sexual practices were more likely to maintain satisfying sexual experience, however, Gilbert et al. (2009), estimated that only 15% of non-androgen deprived PCa couples are actually successful at this. Wittmann et al. (2009) recommend that PCa patients be taught that sex includes much more than the concept of an erection. Hawkins et al. (2009) also suggest that health care professionals encourage cancer patients to try "alternative modes of sexual behavior such as intimate touching, or oral sex without feelings of guilt or inadequacy" (p. 8). Additional support has been found for couples on ADT who were willing to adjust their definitions of emotional and sexual intimacy, as they were more likely to maintain quality marriages (Navon & Morag, 2003).

Furthermore, many couples in this study indicated that it was important to them to be able to maintain intimacy, despite the changes that occurred to their sexual activities. Kuyper and Wester (1998) found that couples with chronic illness, who were unable to maintain intercourse "rarely looked for other forms of intimate contact" (p. 245), while Perez et al. (2002), suggest that sexual intimacy in PCa, 'more than any particular sexual behavior', could be the active ingredient in reassuring couples of affection (p. 292).

Increased communication is associated with both increased satisfaction associated with maintaining sex and to increased affection toward one another. Consistent with this finding, Badr and Carmack Taylor (2008) recommend that PCa couples be counseled to increase healthy spousal communication, given that 'mutual constructive communication'

has been found to help alleviate the negative impact that sexual problems have on marital adjustment. Lack of communication was often associated with greater sexual dysfunction (Badr & Carmack Taylor) and fear of creating negative feelings in the patient (Kuyper & Wester, 1998). Other coping methods were also observed, some of which have been supported in other research, such as increased empathy, understanding, trust (d'Ardenne, 2004), respect, humor (Fergus et al., 2002), perspective taking, realistic expectations (Witmann et al., 2009), team mentality (Badr , Acitelli & Carmack Taylor, 2007), sharing common interests, and being best friends. These coping strategies were illustrated by couples, and could be considered beneficial if suggested to other couples adjusting to ADT. As many couples indicated that they struggled for years before finding help, health care professionals could guide couples through the process of ADT thereby reducing the amount of time they spend struggling and in distress.

Templeton and Coates (2003) found that well-informed ADT patients report less emotional distress and that knowledge can alleviate helplessness and inadequacy. As some couples report that they are not adequately informed about the side effects of treatment, this points to areas in which services to couples should be improved. Perhaps traditional methods of informing patients about potential side effects are not effective. It is possible that couples are being 'informed' about side effects but that they may not 'hear' them due to information overload. Two other possible explanations include that the couples do not understand the information, or that they do not see the relevance of this information because they have not yet experienced the side effects first hand. In order to ensure that patients give informed consent, it must be verified that information about the side effects and implications of ADT are understood.

Another important clinical implication pertains to the areas of struggle relevant to patients on ADT. Other research has shown that changes in sexuality are often associated with reports of self-blame, rejection, sadness, anger and lack of sexual fulfillment (Hawkins et al., 2009) and that diminished sexuality is often associated with disappointment, anger, sadness and grief (Gilbert et al., 2009). d'Ardenne (2004) suggests that in adapting to long-term illness, embarrassment, feeling sexually unattractive, and feeling less valuable can often preclude sexuality. The aforementioned areas of struggle could be assessed and monitored, either through the development of a questionnaire for assessing and monitoring distress associated with struggle, or through the dissemination of knowledge of these areas to clinicians. In this way, couples' adjustment to ADT could be assessed regularly by health care professionals.

Strengths

Through theoretical sampling, saturation was reached at 18 couples, thus this study contains adequate representation of possible couple experiences. Furthermore, the age range (patients: 47 to 83; partners: 32 to 82) and disease demographic range (time since diagnosis: 8 months to 15 years; duration of ADT: ranged from 4 months to 13 years) provide a good sample of those who would be affected by ADT. Additional strengths of this study include efforts taken to ensure validity of the findings such as verification of results with the study participants. Established and reliable methods of coding were utilized (Strauss and Corbin, 1998), codes were meticulously analyzed to ensure accuracy, and interviews and analysis were discussed with the project supervisor and with a colleague to decrease the likelihood that the interpretation was biased. A further advantage of this study relies on the specific methodology which allowed for the

production of a grounded theory which mapped the process through which couples went, this process would not have been captured through traditional quantitative assessment. Additional comments assessing the nature of rigor within qualitative research are included in Appendix A.

Limitations

First, as with all self-report studies, researchers cannot be certain that a participant's identification of a phenomenon is the same as an objective measurement of the presence of that phenomenon. Accordingly, as couples in this study described whether they were satisfied or dissatisfied with their current sexual status, it is possible that they may not actually fit into that category 'objectively'. Second, this study only presents the state of adjustment of one cross-section of a specific sample. Couples are constantly adapting and evaluating and thus move throughout the model at any given moment. Therefore, although one third of the sample fit into each of the three categories, this does not indicate any degree of group membership over time, only at the particular moment they were interviewed. Third, this study examines a specific group of Canadian heterosexual patients and their partners, and therefore may not be applicable to homosexual or ethnically diverse populations.

Future Research

As couples were able to shift their position in the represented model at any time, it is important to consider the impact this can have on their adjustment. How do health care professionals ensure patients are informed about potential ADT related changes? If a couple reaches an acceptance/satisfied state, should a therapist inform of the possibility of becoming sexual? What is the nature of satisfaction?

Future research could aim to answer some of these questions or to test out some hypotheses about intervening with these couples. It is evident that there is a great deal of distress present in many of these couples who are undergoing a struggle. Information regarding ADT related changes and couple coping strategies could be supplied to couples. Specific outcomes could be mapped over time to investigate the stability and/or fluidity associated with each outcome. While many couples identified that they could do without sex as long as their partner was alive (consistent with Harden et al., 2002), other researchers have found that, "what might have seemed like a straight forward decision at first, eventuated for many participants in an often unexpectedly complex and painful period of loss and adjustment later on" (Fergus, Gray and Fitch, 2002, p. 309). Couples could also be informed about the possible pathways of adjustment in order to prepare themselves with realistic expectations for their adaptation. If interventions are implemented, either preemptive or after ADT related changes have begun, successful remediation of distress will lend support for this grounded theory.

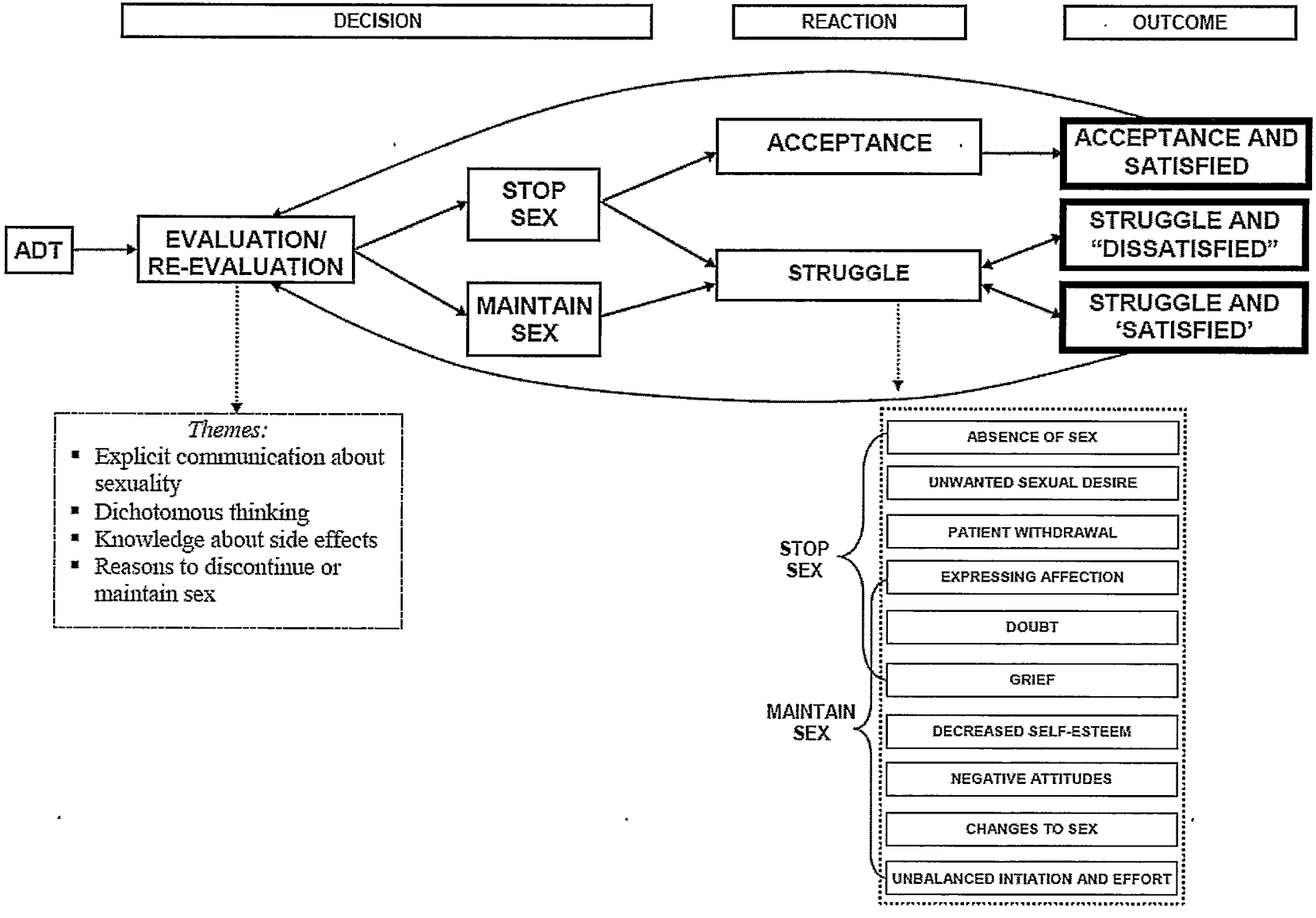
Conclusions

Three important outcomes for couples' adaption to ADT are presented in this paper. First, the traditional expectation about ADT couples' adaption was confirmed for some couples. The acceptance/satisfied group were quickly able to accept a relationship that did not include continued sexual experiences. This outcome may be advantageous for couples in that they are able to become satisfied with their decision. However, because many couples were unaware that they could have persisted with a decision to maintain sex, this finding presents a dilemma for therapists about whether or not these couples should be informed about the possibility of, and protective benefits associated with

maintaining sex. Second, a significant proportion of couples struggle for years to either accept the end of their sexual relationship, or to find a way of being sexual that is satisfying. This struggle/dissatisfied group, has not yet been documented in the literature. It may be this group that would benefit most from intervention. Furthermore, an intervention could be designed from the information gleaned from this study as couples reported both the areas of struggle they encountered, as well as the solutions they utilized to resolve these struggles. The third outcome, the struggle/satisfied group, is also new to the literature (although it has been hypothesized: Aucoin & Wassersug, 2006). Couples in this group found a way of enjoying a changed sexual relationship in the midst of ADT. This finding challenges the widely held belief that satisfying sex is impossible with castrate levels of testosterone. This group provides some indication about methods contributing to their success that may be applicable to the adjustment of other couples affected by ADT. These methods include renegotiating the definition of sex, maintaining mutuality regarding the effort and pleasure received from sexual encounters, maintain clear communication about expectations and assumptions and maintaining affection and intimacy despite a change in the way sexual intimacy is expressed. This finding indicates that it is the responsibility of health care professionals to inform couples that it is not impossible to maintain satisfying sex after beginning ADT.

This report documents the complex adjustment process for patients undergoing ADT, and for their intimate partners. The impact of ADT on the intimate relationship and on sexual adjustment is highlighted, as are the various struggles that are common for couples. Coping methods used by couples are reported and possibilities for future research and psychosocial intervention are suggested.

Figure 1. Model of Couples' Adjustment to Androgen Deprivation Therapy (ADT)


DECISION
REACTION
OUTCOME
ADT
EVALUATION/ RE-EVALUATION
STOP SEX
MAINTAIN SEX
ACCEPTANCE
STRUGGLE
ACCEPTANCE AND SATISFIED
STRUGGLE AND "DISSATISFIED"
STRUGGLE AND 'SATISFIED'
Themes:
Explicit communication about sexuality
Dichotomous thinking
Knowledge about side effects
Reasons to discontinue or maintain sex
STOP SEX
MAINTAIN SEX
ABSENCE OF SEX
UNWANTED SEXUAL DESIRE
PATIENT WITHDRAWAL
EXPRESSING AFFECTION
DOUBT
GRIEF
DECREASED SELF-ESTEEM
NEGATIVE ATTITUDES
CHANGES TO SEX
UNBALANCED INTIATION AND EFFORT

REFERENCES

Allen, C. (1962). Treatment: General principles, in *A Textbook of Psychosexual Disorders,* New York: London University Press.

American Cancer Society. (2007). Prostate cancer. American Cancer Society.

Aucoin, M.W. & Wassersug, R.J. (2006). The sexuality and social performance of androgen-deprived (castrated) men throughout history: Implications for modern day cancer patients. *Social Science and Medicine, 63,* 3162-3173.

Arrington, M.I. (2003). "I don't want to be an artificial man": Narrative reconstruction of sexuality among prostate cancer survivors. *Sexuality & Culture, 7,* 31-58.

Badr, H., Acitelli, L.K., & Carmack Taylor, C.L. (2006). Does couple identity mediate the stress experienced by caregiving spouses? *Psychology and Health, 22,* 211-229.

Badr, H., & Carmack Taylor, C.L. (2008). Sexual dysfunction and spousal communication in couples coping with prostate cancer. *Psycho-oncology,* Epub ahead of print.

Barry, M.J., Delorenzo, M.A., Walker-Corkery, E.S., Lucas, F.L., & Wennberg, D.C. (2006). The rising prevalence of androgen deprivation among older American men since the advent of prostate-specific antigen testing: A population-based cohort study. *BJU International, 98,* 973-978.

Boehmer, U., & Babayan, R.K. (2004). Facing erectile dysfunction due to prostate cancer treatment: Perspectives of men and their partners. *Cancer Investigation, 22,* 840-848.

Canadian Cancer Society/National Cancer Institute of Canada. (2007). *Canadian cancer*

statistics 2007. Toronto, Canada.

Cherrier, M.M., Aubin, S., Higano, C.S. (2009). Cognitive and mood changes in men undergoing intermittent combined androgen blockade for non-metastatic prostate cancer. *Psycho-Oncology, 18*, 237-247.

Cooperberg, M.R., Grossfeld, G.D., Lubeck, D.R., & Carrole, P.R. (2003). National practice patterns and time trends in androgen ablation for localized prostate cancer. *Journal of the National Cancer Institute, 95,* 981-989.

Cresswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks, CA: Sage Publications Inc.

Dacal, K., Sereika, S., & Greenspan, S. (2006). Quality of life in prostate cancer patients taking androgen deprivation therapy. *Journal of the American Geriatrics Society, 54*, 85-90.

Dahn, J.R., Penedo, F.J., Gonzalez, J.S., Esquiabro, M., Antoni, M.H., Roos, B.A. et al., (2004). Sexual functioning and quality of life after prostate cancer treatment: Considering sexual desire. *Urology, 63,* 273-277.

d'Ardenne, P. (2004). The couple sharing long-term illness. *Sexual and Relationship Therapy, 19*, 291-308.

Fergus, K.D., Gray, R.E., & Fitch, M.I. (2002). Sexual dysfunction and the preservation of manhood: Experiences of men with prostate cancer. *Journal of Health Psychology, 7,* 303-316.

Giesler, R.B., Given, B., Given, C.W., Rawl, S., Monahan, P., Burns, D., et al. (2005). Improving the quality of life of patients with prostate carcinoma. A randomized trial testing the efficacy of a nurse-driven intervention. *Cancer, 104*, 752-762.

Gilbert, E., Ussher, J.M. & Hawkins, Y. (2009). Accounts of disruptions to sexuality following cancer: The perspective of informal carers who are partners of a person with cancer. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine,* Epub ahead of print.

Glaser, B. (1998). Doing grounded theory: Issues and discussions. Mill Valley, CA: Sociology Press.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*, 59-82.

Fowler, F.J., McNaughton Collins, M., Walker Corkery, E., Elliot, D.B., & Barry, M.J. (2002). The impact of androgen deprivation on quality of life after radical prostatectomy for prostate carcinoma. *Cancer, 85,* 286-295.

Harden, J., Schafenacker, A., Northouse, L., Mood, D., Smith, D., Peinta, K. et al., (2002). Couples' experiences with prostate cancer: Focus group research. *Oncology Nursing Forum, 29,* 701-709.

Harper, J. M., Schaalje, B. G., & Sandberg, J. G. (2000). Daily hassles, intimacy, and marital quality in later life marriages. *American Journal of Family Therapy, 28*, 1-18.

Hawkins, Y., Ussher, J., Gilbert, E., Perz, J. Sandoval, M., & Sundquist, K. (2009). Changes in sexuality and intimacy after the diagnosis and treatment of cancer: The experience of partners in a sexual relationship with a person with cancer. *Cancer Nursing.* Epub ahead of print.

Kantoff, P.W., Carroll, P.R., & D'Amico, A.V. (2002). *Prostate cancer: Principles and practice* (1st ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

Kuyper, M.B. & Wester, F. (1998). In the shadow: The impact of chronic illness and on the patient's partner. *Qualitative Health Research, 8,* 237-253.

Meng, M.V., Grossfeld, G.D., Sadetsky, N., Mehta, S.S., Lubeck, D.P., & Carroll, P.R. (2002). Contemporary patterns of androgen deprivation therapy use for newly diagnosed prostate cancer. *Urology, 60*(S1), 7-11.

Morse, J. (2007). Reasons for rejection/reasons for acceptance. *Qualitative Health Research, 17,* 1163-1164.

Navon, L., & Morag, A. (2003). Advanced prostate cancer patients' ways of coping with the hormonal therapy's effect on body, sexuality, and spousal ties. *Qualitative Health Research, 13*, 1378-1392.

Ng, C., Kristjanson, L., & Medigovich, K. (2006). Hormone ablation for the treatment of prostate cancer: The lived experience. *Urologic Nursing, 26*, 204-212.

Oliffe, J. (2005). Constructions of masculinity following prostatectomy-induced impotence. *Social Science and Medicine, 60*, 2249-2259.

Perlmutter, M.A., Lepor, H. (2007). Androgen deprivation therapy in the treatment of advanced prostate cancer. *Reviews in Urology, 9*(S1), 3-8.

Perez, M.A., & Skinner, E.C.M., Meyerowitz, B.E. (2006). Sexuality and intimacy following radical prostatectomy: Patient and partner perspectives. *Health Psychology, 21*, 288-293.

QSR International. (2009). NVivo 8 [Computer Software]. Doncaster, Victoria, AUS: QSR International Pty. Ltd.

Smith, M.R. (2004). Osteoperosis and obesity in men receiving hormone therapy for prostate cancer. *The Journal of Urology, 172*(S), 52-57.

Sprenkle, P.C., & Fisch, H. (2007). Pathologic effects of testosterone deprivation. *Current Opinion in Urology, 17*, 424-430.

Stebbins, R.A. (2001). Exploratory research in the social sciences. *Sage University Series on Qualitative Research Methods, Vol. 48,* Thousand Oaks, CA: Sage Publications Inc.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage Publications Inc.

Templeton, H., & Coates, V. (2003). Informational needs of men with prostate cancer on hormonal manipulation therapy. *Patient Education and Counseling, 49*, 243-256.

Warkentin, K.M., Gray, R.E., & Wassersug, R.J. (2006). Restoration of satisfying sex for a castrated cancer patient with complete impotence: A case study. *Journal of Sex & Marital Therapy, 32*, 389-399.

Wassersug, R.J. (2009). Mastering emasculation. *Journal of Clinical Oncology, 27,* 634-636.

Witmann, D., Northouse, L., Foley, D., Gilbert, S., Wood Jr., D.P., Balon, R., et al., (2009). The psychosocial aspects of sexual recovery after prostate cancer treatment. *International Journal of Impotence Research, 21,* 1-8.

Yeh, H.C., Lorenz, F.O., Wickrama, K.A.S., Conger, R.D., & Elder, G.H. (2006). Relationships among sexual satisfactin [sic], marital quality, and marital instability at midlife. *Journal of Family Psychology, 20*, 339-343.

APPENDIX A: Method Details

Method Selection

Much of the research on general PCa patients is often prematurely applied to those who are undergoing ADT. The findings associated with these studies have largely been gathered through quantitative methods. However, in specialist settings, quantitative methods are often limited because specific and validated measures are lacking (Evans, Greenhalgh and Connelly, 2000). The few questionnaires that have been designed to assess health related quality of life and sexual functioning in PCa patients undergoing primary treatment include, the UCLA Prostate Cancer Index (Litwin, Hays, Fink, Ganz, Leake, Brook, 1998) and the Expanded Prostate Cancer Index Composite (Wei, Dunn, Litwin, Sandler & Sanda, 2000). Additional measures deal directly with erectile dysfunction (e.g. the Index of Erectile Function; Rosen et al., 1997; Brief Index of Sexual Function; Reynolds et al., 1988). These questionnaires lack the exploration of other factors specifically related to ADT, such as the loss of arousal and libido, as well as the experience of non-penetrative sexual activities, or sexual activity without erection. These questionnaires also fail to capture the process of adjustment and focus only on the outcome for the patient at that particular time.

As there are unique factors that elude the scope of these questionnaires, a qualitative methodology was implemented in order to truly explore an area in which little is yet known. An open-ended interview was considered to be most advantageous because it encourages participant directed discussion (Stebbins, 2001).

Analytical Process

Interviews were digitally audio-recorded and transcribed verbatim. Following transcription, a grounded theory analysis was utilized to extract themes that emerged in the dialogue. Grounded theory lends itself well to exploring the experience of the individual and to the comparison of varying perspectives on treatment processes (Strauss & Corbin, 1998). Emerging themes were organized hierarchically (Charmaz, 2006; Strauss & Corbin, 1998) and used to help determine relevant areas of struggle and adjustment processes. The grounded theory method allows for researchers to ask a few focused questions, while still allowing the participants to raise important new and unexplored issues (Stebbins, 2001; Creswell, 1998). It was assumed that each participant would be at varying stages in their treatment process and thus would each have a different adjustment experience. Therefore, it is helpful that grounded theory analysis is ideal for the examination of a dynamic and changing process (Glaser & Strauss, 1967; Charmaz, 2006). Through a process called concatenation, the grounded theory that emerges through the analytic process will provide a useful foundation for future studies of either quantitative or qualitative methods. This study is one part of a 'chain-like' process, in which the initial exploration will guide future data collection and analysis, both in the current study and future studies (Stebbins, 2006).

Using the constant comparison method that is foundational to grounded theory analysis, information collected from each couple interview, was compared to subsequent interviews as they were conducted (Charmaz, 2006). The relationships between the emerging concepts were also organized into a consequential matrix (Strauss & Corbin, 1998) so that each couple's story could be compared to various consequential outcomes.

The categories that emerged from the data were then organized into a theory based on the hypotheses that began to emerge about the categories (Figure 1). Once the theory was formulated, couples were organized based whether or not they were satisfied vs. dissatisfied, whether they struggled vs. accepted, and whether or not they maintained or stopped sex. Theoretical sampling was carried out through referral by colleagues who were familiar with couples on ADT, in order to ensure that participants saturated the various categories represented by the data. This resulted in an approximate one third of the sample representing each of the three outcomes presented in Figure 1. Each couples' intricate and unique process was also mapped onto the model in order to verify that the model accounted for the adjustment process of each participant. Furthermore, constant comparison was also applied in order to draw comparisons across interviews and across data to the current literature. The grounded theory that resulted represents a comprehensive set of theoretical propositions about the data and about the relationships between themes relevant for each couple (Glaser, 1998). The study also made clear areas of need for these couples, and ways in which services/resources could be utilized to help patients and their partners adjust to ADT.

It is most important that one consider the goals of this study, which were to create a theory about the adaptation, adjustment, and areas of needs experienced by couples on ADT. In the words of Kurt Lewin; "There's nothing so practical as a good theory" (1951, p. 169), therefore there is great value in the creation of empirical and grounded theory that will allow for clinical application.

Method Selection

When selecting a qualitative method care should be taken to ensure that the method is appropriate for the research question. Once the specific method is chosen, the researcher must familiarize him/herself with the literature on that method. A specific paradigm should be chosen and deviations from that method should be explained, described and accounted for (Cutcliffe, 2000). For example, the current study adhered meticulously the Strauss and Corbin (1998) method of grounded theory described in their book, *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.).

Interpretation of Subjective Meaning and Description of Context

Popay, Rogers and Williams (1998, p. 341) identify that a qualitative health research study is of good quality if it involves an "interpretation of subjective meaning". This criterion is met if the study utilizes the participants' accounts as the sole source of data, and that all subsequent analysis is carried out on this database. An advantage of the grounded theory method and therefore of the current study, is that it is assumed that the propositions made for the sample are immediately valid as they are "grounded" in the data (i.e., that is they emerge right from the data, or the mouths of participants; Stebbins, 2001). Furthermore, Morse (1999) articulates that the data must be interpreted and analyzed for the reader, rather than simply providing an exhaustive list of quotes. The researcher must provide meaning to the reader through "synthesis, interpretation or development of a concept, model or theory" (Morse, 1999, 163). Furthermore, the data sources must also be presented to the reader with an indication of the context in which the

data was collected and the context in which specific quotes were articulated. Quotes presented in the current study were done so through the use of relevant categories. These categories are explained to the reader and integrated with each other in order to provide a meaningful theory/model about the way in which the key concepts are related. Furthermore, context is provided about which participants (i.e. patient or partner) made the statement, and when relevant the interviewer query was also provided.

Participant Validation

A second criterion for evaluating the quality of qualitative health research is the extent to which researchers have attempted to validate their findings with the research participants. It is expected that the account of the findings presented to the study participants "would elicit recognition by the participants as being applicable and relevant to their situations, experience and perceptions" (Horsburgh, 2003, p. 310). When using this validation technique it is important to provide participants with an opportunity to ask questions of the researcher in order to ensure that their views and assessment of the information provided to them are taken into account. A summary of the research findings was distributed to all study participants. Participants were encouraged to provide feedback to the study researcher. Positive comments were made by those who response and two follow-up discussions were carried out in order to clarify participant concerns.

Sampling

Use of sampling techniques ensure that initial data sources are selected for their relevance and identification with a specific population (i.e. purposive sampling) and that subsequent data sources are selected based on attempts to saturate the findings of the study (theoretical sampling; Horsburgh, 2003). Furthermore, situational

representativeness is sought rather than demographic representativeness, however, it is also argued that the feature of good qualitative research is variability (Popay et al., 1998), therefore variable demographic representation can also been seen as valuable. In the current study, both purposive sampling and theoretical sampling were carried out in order to ensure saturation. In addition, the demographics provided are indicative of a broad age range, range of relationship length, and range of disease and treatment characteristics. However, only one-thirds of the sample resided outside Alberta, CAN, an overwhelming majority of the sample was Caucasian, and all participants were in heterosexual relationships.

Reflexivity

Good quality research must also provide acknowledgement that the researcher influences and alters the data collected by interacting with the research participants (Horsburgh, 2003). Therefore the researchers must take into consideration his/her own biases and understandings that may have influenced the data at all phases of the study including data collection, analysis, synthesis and presentation of results. In accordance with the Strauss and Corbin (1998) method researcher reflexivity was considered at all points of the study. The researcher encouraged participants to speak about interview topics candidly and reserved judgment on the interview data. During the analysis phase, the researcher talked with a colleague and the senior researcher in order to verify the coding procedure with someone who was 'outside' the analysis. Participant validation was also carried out. Furthermore, the researcher acknowledged that coming from a clinical psychology background likely influenced the reporting of data and classification of couple outcomes in a "problem" and "solution" focused fashion.

Generalizabtility

Though generalizability is never the goal of a qualitative study it is still relevant when evaluating its quality. For example, rather than provide an explanation of the breadth of experience of a group of patients, grounded theory aims to provide an intensive exploration of a specific group of research participants. It is also understood that exploratory research is not definitive, but it is substantive (i.e., focused on a specific group in a specific place and time; Stebbins, 2001). Furthermore, using the grounded theory method, the theory that comes from the data is general in nature. A good quality study should render a synthesis or theory that can and should be 'applied' to similar populations (Morse, 1999; Stebbins, 2001). The current study adheres to these principles in that it provides a substantive rather than general theory about couple's adjustment to ADT. It does however provide valuable and specific information about ADT related changes that are relevant to couples affected by ADT.

Credibility and Relevance

The results of a good qualitative health research study also are deemed as credible to researchers who study in the same areas and to patients and health care professionals who directly work within the area explored within the study. It must also be seen to offer something new to the literature (Morse, 1999; Pope & Mayes, 2000). The current study makes significant contributions to the literature, which are clearly outlined in the conclusions section of the report. Furthermore, a medical oncologist, a health psychologist, a grounded theory researcher and a prolific contributor to the ADT literature have read and commented on this report, and have determined it credible.

Additional References

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage Publications Inc.

Cutcliffe, J.R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing, 31,* 176-1484.

Evans, S., Greenhalgh, J., & Connelly, J. (2000). Reviewing and selecting outcome measure for use in routine practice. *Journal of Evaluation in Clinical Practice, 6,* 379-93.

Glaser, B.G. & Strauss, A.L. (1967). *Discovery of Grounded Theory.* Chicago, IL: Aldine Publishing Company.

Horsburgh, D. (2003). Evaluation of qualitative research. *Journal of Clinical Nursing, 12,* 307-312.

Lewin, K. (1951). Field theory in social science; selected theoretical papers. D. Cartwright (ed.). New York: Harper & Row.

Litwin, M.S., Hays, R.D., Fink, A., Ganz, P.A., Leake, B., & Brook, R.H. (1998). The UCLA Prostate Cancer Index: Development, reliability, and validity of a health-related quality of life measure. *Medical Care, 36,* 1002-1012.

Morse, J. Silent debates in qualitative inquiry. *Qualitative Health Research, 9,* 162-165.

Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research, 8,* 341-351.

Mayes, N. & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative health research. *BMJ, 320,* 50-52.

Reynolds, C.F., Frank, E., Thase, M.E., Houck, P.R., Jennings, J.R., et al. (1988). Assessment of sexual function in depressed, impotent, and healthy men: Factor analysis of a brief sexual function questionnaire for men. *Psychiatry Research, 24,* 231-250.

Rosen, R. C., Riley, A., Wagner, G., Osterloh, I. H., Kirkpatrick, J., & Mishra, A. (1997). The International Index of Erectile Function (IIEF): A multidimensional scale for assessment of erectile dysfunction. *Urology, 49,* 822-830.

Stebbins, R. A. (2006). Concatenated exploration: Aiding theoretic memory by planning well for the future. *Journal of Contemporary Ethnography, 35,* 483-494.

Stebbins, R. A. (2001). Exploratory research in the social sciences. *Sage University Series on Qualitative Research Methods, 48,* Thousand Oaks, CA: Sage Publications Inc.

Wei, J., Dunn, R., Litwin, M., Sandler, H., & Sanda M. (2000). Development and validation of the Expanded Prostate Cancer Index Composite (EPIC) for comprehensive assessment of health-related quality of life in men with prostate cancer, *Urology, 56*, 899-905.

Coding of Categories Related to "Relationship" Theme

Attempted Strategies	Adapt sex	
	Decide not to have sex	Draw a line about sex Find ways to show affection Remember what was good "More going for us than sex"
	Determination	
	Grieve	
	Perspective taking	
	Requires planning	
	Try to become closer	
Challenges	Changes to self-esteem	
	Fatigue	
	Doubt	
	Grief	
	Increased frustration	
	Isolation	
	Patient Withdrawal	
	Lack of motivation	
	Non-mutuality	
	When there is still desire	
Changes to Intimacy	Can be physical without sex	
	Changes in affection	
	Don't feel connected	
	Need for physical intimacy	
	Still desire connection	
	When they feel closest	
Communication	Challenges in communication	
	Said they didn't talk about it	
	Increased understanding	
	Openness	
	Role in facilitating problems	
	Talk about what's difficult	
Evaluation of Decision	Dichotomous thinking	
	Decision making process	
Individual Roles	Fear of becoming platonic	
	Said there were no changes	
	She takes more responsibility	
	Sleeping arrangements	
	Team	
Support of Partner	Advocate	
	Caregiver	
	Discredit her understanding	

	Encourage		
	Help with research		
	Instrumental support		
	Just be there		
	Nagging		
	Mutual support		
	Understanding		
	Uninvolved		
The Sexual Experience	Attitude towards sex		
	Challenges to sex	Changes foreplay	
		Orgasm present?	
		Reasons to not engage	Almost like work Emotionally painful Grief Not a priority Not mutual Requires planning Just give up
		Reasons to engage	Becomes even better Changed goals Fight for it Hormones wear off She starts to initiate Maintain intimacy Pleasure her Priority Relief Role of laughter Have an erection
	Indicated sex was 'absent'		
	Reaction to loss of libido	Acceptance	Balance of desire Indifference Relief Satisfaction Still have desire
		Struggle	Anger Confusion Demoralization Disappointment Fears Frustration Grief Emasculation

APPENDIX B: Demographic Summary

Age	Patients (n = 18)	47 - 83 (M = 65.4) yrs.
	Partners (n = 18)	32 - 82 (M = 61) yrs.
Length of Time Since PCa Diagnosis		8 mos. - 15 yrs.
Length of ADT Administration		4 mos. - 13 yrs.
Length of Intimate Relationship	Married (n = 16 couples)	1 mos. - 60 yrs.
	Dating (n = 2 couples)	1 yr. - 5 yrs.
Sexual Status	'Stopped' (n = 9 couples)	
	'Maintained' (n = 9 couples)	

APPENDIX C: Reasons to Discontinue or Maintain Sexual Experiences

Reasons to Maintain Sexual Experiences

Importance. One partner, who wasn't sexual with her partner before his prostate cancer treatment actually became sexual with him in order to decrease the probability of losing his erectile function while he was on ADT. She described, "When all of this was happening I could see that it was so important to him, I wanted to facilitate that." She engaged sexually for his benefit and though 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.

Another couple, who met after he had begun his ADT, prepared themselves for a relationship in which they would never be able to engage in sex. This was the only couple in the sample who had initially decided to stop sex, had then decided to maintain sex and was not struggling through the process at the time that they were interviewed. Furthermore, some of the women simply described that sexual experiences were enjoyable and important to them; therefore the couple made sexuality a priority in the relationship.

> I don't know whether other women struggle with this, but I do. I'm the one with the libido. I'm the one. I want sex. And I want it with my husband. He's the only person I want it with. I don't want to lose that part of our relationship which is so precious.

Intimacy. Another theme commonly described among those couples who were still sexual, was that sexual encounters allowed for intimacy that could not be replicated in any other way. For these 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."

Release. The following couple described this phenomenon, as well as the idea that sexual encounters can provide a necessary release for individuals.

> It's part of a relationship that a couple has, the sexual things, there is that release that you need now and then. I think that you need it and it is part of your love, and part of your relationship. And you know that's what I feel bad about for him, because maybe he is not experiencing it like he used to. And maybe that's part of this whole hormone treatment. And I feel like, just doesn't do very well with it.

Enjoyment. Sexual experiences, though different than they were before can also be enjoyable in new ways. For example, one 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." The following partner reported on the humor describing a time in which she attempted to increase romanticism 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."

Improvement. Unexpectedly, some couples identified that since the ADT, their sexual experiences had improved. For example, one couple appreciated having predictable erections that lasted a long time, due to the use of erectile aids such as injections,

> Well, when you're young your erection can last for forever and you can get another one before too long, but as you age you have to capitalize on the time when the erection is there. But now with injections the erection can go on for an hour or two, so there's not the rush.

Another couple explained that sex before ADT was often impeded by his 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, more in the beginning when we met, there was a period there before this happened where umm, like 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 couple actually reported that their sexual experience became more spontaneous. She had always felt as if she participated in sexual activities as a habit, not because they were a priority for her, whereas after ADT, sexual activities could be initiated when she experienced spontaneous desire,

> Before we kind of got into a habit, whereas now it's not like that because he's not necessarily wanting to engage in sex, any kind of sex, and then all of a sudden you know we both might want to at the same time. It's a little more spontaneous.

Made Up for Other Faults. Some couples reported that when other things were not going right in their lives or in the marriage, that being able to be sexually intimate could often put them back on track. This man spoke about how a good sex life made up for his other faults, "Having a good sex life makes up for a lot of other...ah a husband's sins like forgetting to buy butter to bring home, or you screw up in other places. If you have a good sex life, its, 'alright now, we're back, life's good'.

Reasons to Discontinue Sexual Experiences

Non-Mutual Experience of Libido. Most of the men assumed that because they ceased to desire sex, that their sexual lives would be terminated. The idea of continuing to engage sexually for the benefit of their wives was often overlooked. One husband reported, "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." Interestingly, there were a few cases in which the men talked about the possibility of using sex toys as aids in the bedroom. In these few cases, the women were rarely receptive to the idea. For example, "I offered to buy her a, something that requires batteries for Christmas and she said no [laughs]". Another patient suggested how he could focus on pleasing his wife and how he was willing to consider the use of sex toys,

> She would play with me and nothing happened...I could play with her, you know? It's different then (Laughs). Or, [I] could go out and buy one of those artificial deals', like...you know? It's something to think about.

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 [she laughs]." Another woman talked about how she learned not to act on her sexual desires because she assumed that her husband's loss of libido negated any potential for a sexual encounter, "I would have felt like it, but knowing how he was, I would not have gone ahead and sort of suggested anything."

Another woman reported that it was just too much work to try to get her partner interested 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.

Non-Mutual Experience of Pleasure. Some of the women in the study indicated their strongly held perception that they should not be the only partner able to receive sexual pleasure. Therefore these women subscribed to a dichotomous line of thinking in which both partners must enjoy the sexual experience, and in some cases must even have equally enjoyable sexual experiences in order for sex to be considered worthwhile. For example, 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 is shown in a tendency for many of the female partners to decide that their relationship should no longer involve sexual activity. In most cases, a sexually uninterested husband did not dispute this decision and the couple became non-sexual.

Non-Mutual Experience of Effort. Several of the women who were still engaging in sexual activity with their partners, also reported that the nature of their sexual experiences changed. In many cases, the sexual encounter 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 the only one bringing anything to the table, but it didn't stop me from feeling angry about that loss.

Another woman shared, "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."

Non-Mutual Experience of Willingness. Many of those women who were still engaging in sexual activities reported difficulty in "asking" their partner to participate in sex. Several women indicated that they found it embarrassing to have to 'ask' for sex, for others initiating sex meant adjusting to a significant change in roles, still, others felt that if they had to ask for "help" in the bedroom that his lack of enthusiasm translated to the assumption that he must see sexual activity as a chore. The following exemplar illustrates the layers present in one partner'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 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?

She describes engaging in sexual activities in which she begins with self stimulation; however, she requires his 'help'. Having to ask him for help is associated with feelings selfishness. She also expressed concern for her partner's self-esteem and how it may have be impacted based on 'resorting' to the use of sex toys. Interestingly, he responded to her concern by saying, "Its fine. I'm fine with it because I know I can't get an erection, I'd rather satisfy my partner". Still, she endorsed these concerns despite his opinion that he was 'fine with it'. She further reported,

> 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 to, you know, be satisfied but I've limited it to probably once a week sometimes once every two weeks.

Priority. For some couples, getting used to the idea that they were no longer sexual was quite straightforward because sex was no longer a priority for them. For example, one couple in their eighties had already ceased to be sexual almost a decade earlier. While it may be assumed that age could play a role in whether or not a couple considers sexuality a priority, similar statements were made by people in a wide age range. Another man in his sixties reported that he got used to the idea with the passage of time, "After about 4 or 5 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 fifties, 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." While another woman in her early forties actually 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".

Attempts at sex are too emotionally painful. Both patients and partners indicated that the sexual act, though potentially enjoyable, brings back too many memories of lost experiences and therefore is too emotionally painful to continue to engage in. Several men indicated that attempting to engage in sex was a constant reminder of being a failure as they did not want to "start something [they] can't finish". One patient described, "[Sex is] infrequent, let's put it that way. It's not something that you want to do too often because it's uh, you know? But yes…we still do have it." Another patient specifies the dilemma that occurs when they try to engage sexually,

> "[If I] give her some sexual pleasure, I won't be able to have any response on my own and it, if I, she feels that if I try to do anything with her that it will just make me feel way worse and that's why she sort of wants to avoid it.
>
> 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, it's, it's sad because you, just can't get anywhere.

Fatigue. As fatigue was identified as one of the challenges associated with ADT, it also played a role in whether or not the patient had enough energy to engage in sex. The patients also described too physically exhausted to help with household chores and unmotivated to plan and execute to tasks or social activities. Therefore fatigue impaired both physical capacity and likely one's motivation to initiate or participate in sexual activity.

Summary

The evaluation of reasons to discontinue or maintain sex was particularly relevant to those in the struggled/satisfied and struggled/dissatisfied groups. Those in the acceptance/satisfied group may have endorsed the aforementioned reasons to support why they chose to stop sex. Because they made their decisions so quickly, it is also

possible that they did not require further reasons beyond 'sustaining life' to make their decision.