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Sexual health care in prostate cancer for men and their partners

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Part III

Sexual health care in prostate cancer: Partners

Chapter 5

Treatment-related sexual side effects from the perspective of partners of men with prostate cancer

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Introduction

Due to increased prostate-specific antigen (PSA) screening, more men are diagnosed with low-risk prostate cancer (PCa) (1). The most commonly reported side effects of PCa treatment are erectile dysfunction (ED), anejaculation and changes in sexual performance (2-4). Due to treatment-related sexual side effects, frequency of sexual activity may decline after treatment (5, 6). These secondary effects can negatively affect a man's self-esteem and contribute to partial loss of masculine identity, leading to possible impairment of intimacy with their partners (7, 8).

Unfortunately, partners are rarely involved in urology consultations when sexual functioning is discussed (9). Literature shows that partners of men who have undergone treatment for PCa experience unmet sexual and support needs (10-12). Treatment-related side effects can cause sexual problems and can have a negative influence on the relationship; accordingly, PCa has been described as a 'relationship disease' (13-15).

Sanda et al. performed a study whereas also partners could indicate as to what extent sexual function had become a problem after treatment (16). Forty-four percent of the partners of men who had undergone a prostatectomy reported moderate to big sexual problems. As to clinical characteristics, older age and high PSA levels at diagnosis have been identified as associated factors with decrease in sexual function among patients (16, 17). However, little research has been conducted among partners concerning clinical factors associated with the extent of sexual health issues.

The aim of this cross-sectional study is to evaluate to what extent partners found it difficult to deal with treatment-related sexual side effects and to what extent partners experienced sexual problems after treatment. Moreover, to investigate associated factors such as demographic characteristics, number of comorbidities, clinical factors (e.g. PSA level, tumor, node and metastasis (TNM) staging, Gleason grading) and type of treatment between to what extent partners found it difficult to deal with treatment-related sexual side effects and to what extent partners experienced sexual problems after treatment. In addition, to analyze if the patient's erectile complaints and decline of sexual activity after treatment correspond to how difficult partners found it difficult to deal with sexual side effects and the extent of experienced sexual problems. Furthermore, we sought to investigate if sexual side effects have a positive or negative impact on the relationship between men treated for PCa and their partners.

Material and methods

Procedure

Recruitment of partners took place through men who were treated for PCa and registered at the oncology registration of Leiden University Medical Center. Based on the hospital's declaration code for PCa, a list was obtained with patients diagnosed with or treated for PCa between 2013 and 2015. Hence, the list also comprised patients who were diagnosed with or treated for PCa before 2013 and had received an (additional) treatment between 2013 and 2015. Patients treated (after active surveillance) with laparoscopic radical prostatectomy (LRP), brachytherapy (BT), intensity-modulated radiotherapy (IMRT) and/or hormonal therapy (HT) were included. Patients under active surveillance were excluded. Additional patient data obtained from the oncology registration included age, PSA level, TNM staging, Gleason grading and type of treatment.

Separate information letters and consent forms were sent to 590 eligible men and their partners, in which objectives and content of the study were explained. With affirmative consent, questionnaires were sent. Questionnaires from men and their partners were correspondingly encoded in order to be able to afterwards pair the partner's questionnaire to the patient's questionnaire and his clinical characteristics. To warrant privacy of both men and partners, the questionnaires were sent in separate envelopes, both provided with a post-paid envelope to return the completed questionnaire. Men and partners unwilling to participate, could indicate unwillingness on the consent form, whereas a question was added to obtain reason for non-participation.

Materials; questionnaires

Both questionnaires were designed by the authors, based on study aim, review of literature and previously designed questionnaires of published studies by the research group. The questionnaire completed by patients assessed items such as length of relationship in years, two three-point Likert scale measuring the extent of ED before and after treatment (ranging from 'no erectile complaints' to 'major erectile complaints'), two questions assessing the presence of sexual activity before and after treatment and a question to determine the impact of sexual side effects on the relationship ('no impact', 'negative impact' and 'positive impact'). The questionnaire completed by partners comprised demographic characteristics, comorbidities, a four-point Likert scale inquiring difficulty degree to deal with treatment-related sexual side effects (ranging from 'no difficulties' to 'very difficult'), a three-point Likert scale concerning the extent that partners experienced sexual problems after treatment (ranging from 'no problems' to 'severe problems') and, equally to the patient's questionnaire, the

question concerning impact of sexual side effects on the relationship. Of patients who did not engage in the study, but their partner did, length of relationship, erectile complaints, sexual activity and clinical characteristics remained unknown. Due to the small number of homosexual individuals who responded to this study and in order to maintain the group uniform, we decided to solely analyze heterosexual partners.

Statistical analysis

Demographic characteristics, comorbidities, clinical characteristics (PSA level, TNM staging, Gleason grading), type of treatment, degree of erectile complaints and sexual activity, and variables concerning the extent of how difficult partners found it to deal with treatment-related sexual side effects and experienced sexual problems were analyzed using descriptive statistics. Numerical variables were described with mean (SD) or median (range), and categorical variables with number (%). Bivariate associations between level of 'finding it difficult to deal with treatment-related sexual side effects' or 'experiencing sexual problems' and 1) demographic characteristics, 2) number of comorbidities, 3) clinical characteristics, 4) type of treatment were analyzed in partners of men with an increase in erectile complaints after treatment using the Fisher's Exact test, One-way ANOVA test and Kruskal-Wallis test. Associations between two ordinal variables were analyzed using Linear-by-Linear association. Analyses were performed with SPSS Statistics version 23.0. Two-sided p values <0.05 were considered statistically significant.

Ethics

Ethical approval was granted by the Institutional Review Board at Leiden University Medical Center.

Results

Out of 590 information letters and consent forms sent, a total of 353 partners (59.8%) sent their consent forms back; whereas 190 partners (53.8%) provided an affirmative consent and 137 partners (38.8%) did not agree to participate. Most named reasons were 'not interested' (34.5%), 'questions are too personal' (18.5%), and 'improvement in the field of sexuality is not important' (14.9%). Twenty-six patients (7.4%) sent consent forms of the partner back disclosing that they did not have a partner (anymore). In total, 174 partners returned a completed questionnaire, including 12 partners of whom the patient did not participate in the study. Eleven questionnaires were from partners of men under active surveillance. Three questionnaires were from male partners. Hence, 160 questionnaires were analyzed.

Table 1. Demographic characteristics and clinical variables.

	n (%)
Age of partners (years)	
Mean 65.4 (SD 7.3)	160 (100.0)
Age of men (years)	
Mean 69.0 (SD 6.6)	148 (92.5)
Duration of relationship (years)	
Median 45.0 (range 3 – 60)	
Occupation of partners	
Employed	43 (26.9)
Unemployed	13 (8.1)
Retired, employed	17 (10.6)
Retired, unemployed	87 (54.4)
Education of partners	
No qualification/elementary school	10 (6.3)
Lower vocational education	76 (47.5)
Intermediate vocational education	29 (18.1)
Higher secondary education	15 (9.4)
Higher education	30 (18.8)
Number of comorbidities of partners	
0	44 (27.5)
1	46 (28.8)
2	43 (26.9)
≤3	27 (16.9)
Prostate-specific antigen level (µg/L)	
Median 11.0 (range 2 – 838)	
Tumor, nodes and metastasis (TNM) staging	
T – Local stage	135 (84.4)
N – Regional stage	8 (5.0)
M – Distant stage	5 (3.1)
TNM staging unknown[a]	12 (7.5)
Gleason grading	
6	59 (36.9)
7	59 (36.9)
8	15 (9.4)
9	12 (7.4)
Gleason grading unknown[b]	15 (9.4)
Type of treatment	
Laparoscopic radical prostatectomy (LRP)[c]	41 (27.7)
Brachytherapy (BT)	18 (12.2)
Intensity-modulated radiotherapy (IMRT)	35 (23.6)
IMRT combined with hormonal therapy (HT)[d]	43 (29.1)
HT	11 (7.4)

a. No TNM staging available due to non-participation (n = 12)
b. No Gleason grading available (n = 3), no Gleason grading available due to non-participation (n = 12)
c. Including LRP combined with IMRT (n = 5) and LRP combined with HT (n = 1)
d. Including BT combined with HT (n = 8) and IMRT combined with LRP and HT (n = 4)

Demographic characteristics of partners

The mean age of partners was 65.4 years (SD 7.3), almost half of them had lower vocational education level (47.5%, n = 76). Further details on demographic characteristics are described in Table 1.

Comorbidities of partners

Hypertension (31.3%), hypercholesterolemia (25.6%) and musculoskeletal disorders (24.4%) were the comorbidities reported most often. Other comorbidities mentioned were adiposity (11.9%), chronic respiratory diseases (9.4%) and diabetes mellitus (6.9%). Twenty-eight percent (n = 45) did not have any comorbidities. The median number of comorbidities was 1.0 per partner (range 0 – 6).

Clinical characteristics of patients

Out of 253 completed questionnaires returned by men with PCa, a total of 148 questionnaires could be paired to participating partners. The mean age of men was 69.0 years (SD 6.6), and the majority had localized PCa (84.4%, n = 135). Most men were treated with a combination of IMRT and HT (29.1%, n = 43), followed by LRP (27.7%, n = 41) and IMRT (23.6%, n = 35). Further details on clinical characteristics are shown in Table 1.

Erectile complaints and sexual activity

Before treatment, 63.5% of men (n = 94) had no erectile complaints, 32.4% (n = 48) had minor erectile complaints and 4.1% (n = 6) had major erectile complaints. After treatment, 15.6% (n = 23) had no erectile complaints, 29.3% (n = 43) had minor erectile complaints and 55.1% of men (n = 81) had major erectile complaints. A total of 104 men (70.7%) experienced an increase in their erectile complaints after PCa treatment: 26.0% (n = 27) went from no erectile complaints to minor erectile complaints, 46.2% (n = 48) from no erectile complaints to major erectile complaints and 27.9% (n = 29) went from minor erectile complaints to major erectile complaints. Prior to treatment, the majority was sexually active (96.6%, n = 143). After treatment, half of men were not sexually active anymore (51.0%, n = 75)

Partner's perspective on sexual side effects and experienced sexual problems

Out of all partners of men with an increase in erectile complaints, around a third (36.4%, n = 36) had no difficulties dealing with sexual side effects; whilst almost half of them (44.4%, n = 44) found it slightly difficult to deal with sexual side effects and 19.2% (n = 19) found it moderate to very difficult. Thirty-seven percent of the partners (n = 38) reported no sexual problems after treatment; whereas more than half of them (51.0%, n = 53) indicated moderate sexual problems and 12.5% (n = 13) severe sexual problems.

Out of the 36 partners who did not find it difficult to deal with sexual side effects, 22.2% (n = 8) reported to have experienced moderate sexual problems after treatment. Eleven percent of the 44 partners (n = 5) who indicated to have find it slightly difficult to deal with sexual side effects, reported severe sexual problems.

Factors associated with perspective on sexual side effects and sexual problems

No significant associations were identified between partners who found it difficult to deal with sexual side effects and demographic characteristics, number of comorbidities, clinical characteristics (PSA level, TNM staging, Gleason grading) and type of treatment (Table 2).

Partners with a lower education level experienced less sexual problems after treatment than partners with a higher education level ($p < 0.001$). Furthermore, no significant associations were found between having experienced sexual problems and age of partner ($p = 0.079$), age of patient ($p = 0.229$), length of relationship ($p = 0.132$), partner's occupation ($p = 0.720$), partner's number of comorbidities ($p = 0.458$), PSA level ($p = 0.343$), TNM staging ($p = 0.664$), Gleason grading ($p = 0.196$) and type of treatment ($p = 0.133$). A high percentage of having experienced moderate to severe sexual problems was found among partners of men treated with LRP and IMRT (respectively 72.5%, n = 29 and 80.0%, n = 16). Partners of men treated with IMRT combined with HT were more or less divided in two halves: 48.5% (n = 16) experienced sexual problems and 51.5% (n = 17) experienced no sexual problems (Figure 1).

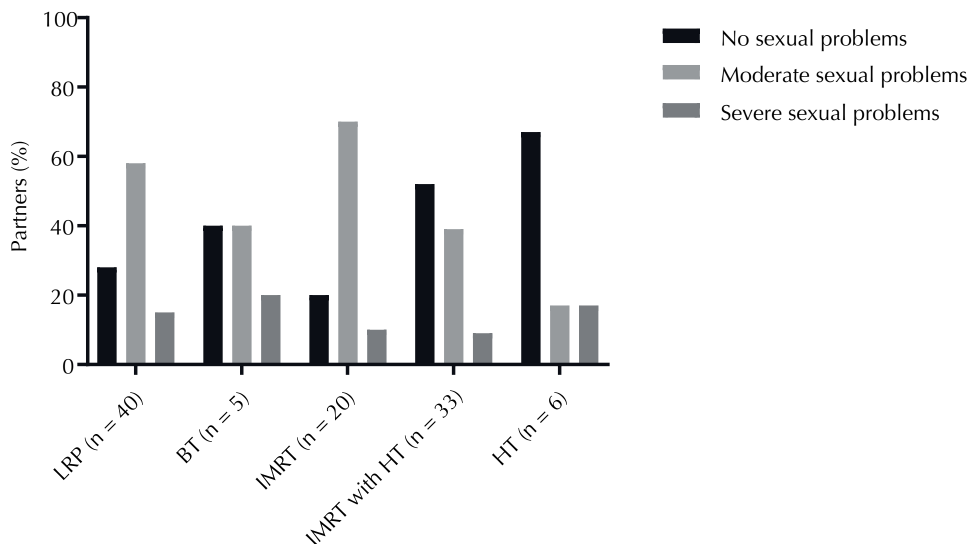
Table 2. Associations between dealing with sexual side effects and demographic and clinical characteristics.

	No difficulties n (%)	Slightly difficult n (%)	Moderately difficult n (%)	Very difficult n (%)	*p*-value
Age of partners (years)					0.525[c]
	Mean 65.8 (SD 7.6)	Mean 64.4 (SD 6.3)	Mean 64.7 (SD 8.9)	Mean 60.5 (SD 10.1)	
Age of men (years)					0.711[c]
	Mean 69.1 (SD 7.2)	Mean 67.4 (SD 6.2)	Mean 67.7 (SD 7.9)	Mean 69.3 (SD 5.3)	
Duration of relationship (years)					0.407[b]
	Median 45.0 (range 5 – 60)	Median 44.5 (range 3 – 55)	Median 41.0 (range 5 – 55)	Median 27.5 (range 7 – 49)	
Occupation of partners					0.974[a]
Employed	10 (32.3)	15 (48.4)	4 (12.9)	2 (6.5)	
Unemployed	3 (42.9)	2 (28.6)	2 (28.6)	-	
Retired, employed	4 (40.0)	5 (50.0)	1 (10.0)	-	
Retired, unemployed	19 (37.3)	22 (43.1)	8 (15.7)	2 (3.9)	
Education of partners					0.057[d]
No qualification/elementary school	1 (20.0)	3 (60.0)	1 (20.0)	-	
Lower vocational education	24 (49.0)	19 (38.8)	5 (10.2)	1 (2.0)	
Intermediate vocational education	4 (20.0)	10 (50.0)	6 (30.0)	-	
Higher secondary education	2 (50.0)	5 (62.5)	-	1 (12.5)	
Higher education	5 (29.4)	7 (41.2)	3 (17.6)	2 (11.8)	
Number of comorbidities of partners					0.253[b]
	Median 1.0 (range 0 – 4)	Median 1.5 (range 0 – 4)	Median 2.0 (range 0 – 4)	Median 0.5 (range 0 – 3)	
Level of prostate-specific antigen (µg/L)					0.349[b]
	Median 13.0 (range 5 – 139)	Median 10.5 (range 6 – 838)	Median 11.0 (range 2 – 60)	Median 28.0 (range 10 – 49)	
Tumor, nodes and metastasis (TNM) staging					0.146[d]

T – Local stage	30 (33.3)	42 (46.2)	15 (16.5)	4 (4.4)	
N – Regional stage	4 (80.0)	1 (20.0)	-	-	
M – Distant stage	2 (66.7)	1 (33.3)	-	-	
Gleason grading					0.229[d]
G6	9 (28.1)	18 (56.3)	3 (9.4)	2 (6.3)	
G7	15 (32.6)	19 (41.3)	10 (21.7)	2 (4.3)	
G8	7 (70.0)	2 (20.0)	1 (10.0)	-	
G9	3 (37.5)	4 (50.0)	1 (12.5)	-	
Type of treatment					0.256[a]
Laparoscopic radical prostatectomy	12 (30.8)	18 (46.2)	8 (20.5)	1 (2.6)	
Brachytherapy	1 (25.0)	2 (50.0)	-	1 (25.0)	
Intensity-modulated radiotherapy (IMRT)	7 (38.9)	11 (61.1)	-	-	
IMRT combined with hormonal therapy (HT)	12 (37.5)	12 (37.5)	6 (18.8)	2 (6.3)	
HT	4 (66.7)	1 (16.7)	1 (16.7)	-	

a. Fisher's Exact test
b. Kruskal-Wallis test
c. One-way ANOVA test
d. Linear-by-Linear association

Figure 1. Abscence and presence of sexual problems per type of treatment in partners of men with increased erectile complaints after treatment.



Out of the 43 men who indicated no increase in erectile complaints after treatment, 30.6% of their partners (n = 11) found it difficult to deal with sexual side effects and 25.6% partners (n = 11) experienced sexual problems. Twenty-five men already had erectile complaints prior to treatment and reported no increase in erectile complaints after treatment. Almost half of their partners (45.5%, n = 10) found it difficult to deal with sexual side effects and ten of their partners (40.0%) experienced sexual problems after treatment.

Out of all men who did not pursue sexual activity after treatment, 28.0% (n = 21) indicated no increase in erectile complaints after treatment. Twenty-five percent of their partners (n = 5) found it difficult to deal with sexual side effects and 19.0% (n = 4) experienced sexual problems; within these groups, three partners had both difficulties dealing with sexual side effects and experienced sexual problems.

Impact of sexual side effects on relationship

Sixty-three percent of partners (n = 65) and 58.4% of men (n = 59) experienced no impact of sexual side effects on their relationship. One in three partners (33.7%, n = 35) stated to have encountered negative impact, whereas a third of men (33.7%, n = 34) gave the same answer. Positive impact was experienced by 3.9% of the partners (n = 4) and by 8.0% of men (n = 8).

Discussion

This study showed that more than half of female partners of men with a reported increase in erectile complaints after PCa treatment found it difficult to deal with treatment-related sexual side effects and that partners experienced sexual problems after treatment. The majority of men in this study reported an increase in their erectile complaints after treatment together with discontinuation of their sexual activity. Wittmann et al. studied couples in their recovery as to altered sexual health after prostatectomy (18). Postoperatively, 95% of men experienced ED leading to loss of sexual desire and with only half of them experiencing satisfactory orgasms. Partners of these men reported disappointment regarding altered sexuality after treatment. It is indisputable that PCa treatment has important consequences for the sexual health of both patient and partner. When it comes to PCa patients, several studies have investigated possibilities of sexual rehabilitation, including penile rehabilitation, in order to improve sexual health after treatment (19-21). However, partners are generally neglected when it comes to sexual recovery after treatment (22-24). Partners feel excluded during follow-up consultations, although consequences of sexual side effects also apply to them (22). Partners have indicated that healthcare professionals barely provide them attention, regardless of them feeling affected by the diagnosis and treatment outcomes.

A few partners of men with an increase in erectile complaints, had no difficulties dealing with sexual side effects, yet reported having experienced sexual problems. Men tend to focus more on the physical aspect of impaired sexuality, e.g. erectile dysfunction as a result of PCa treatment. Partners, meanwhile, tend to focus more on other aspects of sexuality, such as relational issues (25). The World Health Organization defines sexuality as "…a central aspect of being human throughout life which encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction." (26). Thus sexuality does not only encompass sex, but also eroticism, pleasure and intimacy. It is therefore conceivable that partners may not be bothered by erectile complaints; yet experience problems in the area of pleasure and intimacy which may lead to sexual problems.

Partners with a lower education level experienced less problems with sexuality after treatment than partners with higher education levels. Zhang et al. studied factors associated with sexual dysfunction among women in Hong Kong (27). The authors found that women with high education levels reported lack of interest in sex less frequently compared to women with low education levels. So it could be concluded that women with high education levels have a higher libido than women with lower education levels. It can partially explain the reason why in this study partners with

a lower educational level reported less sexual problems. It could also be the case that partners with lower education levels find sexual problems less important. A study performed among cancer survivors and their relatives determined higher levels of anxiety in people with low socio-economic levels (28). If the focus among partners who have a lower education is centralized on the disease and the outcome of its treatment, it is feasible that they may less likely worry about the consequences of the treatment; let alone sexual problems.

Furthermore, a great number of partners of men treated surgically or with IMRT reported sexual problems after treatment. Consistent with one of the outcomes in a study performed by Ramsey et al. whereas partners of men treated with radical prostatectomy reported worsening of their sexual relationship significantly more often compared to partners of men who were non-surgically treated (29). On the contrary, partners of men treated with HT reported to have experienced less sexual problems. Considering ageing and decline of sexual activity are associated; partners of men treated with HT, who are in most cases older and are more likely to have a higher rate of comorbidities, may not benefit from sexual recovery after treatment when compared to younger partners (30). Furthermore, older women are less likely to be sexually active than older men; partly by means of their peri- or postmenopause (30, 31).

In this study, several discrepancies were found between statements made by partners and men as to sexual side effects. Notwithstanding men indicated no increase in erectile complaints, partners still found it difficult to deal with sexual side effects and experienced sexual problems. It is feasible to believe that men may underestimate their erectile function and that partners attenuate the problems that ED as a consequence of treatment may have caused (10). Although women indicate to not be in need of sexual supports, they do encounter issues around the frustrations of their partner; men are confronted with treatment-related ED and its consequences of feeling less masculine (32). Partners may feel like they do not want to put any pressure on sexuality and could therefore experience more sexual problems than actually having difficulties dealing with sexual side effects. Alongside, there were men who were still able to perform sexually, yet did not pursue sexual activity after treatment whereas a few partners had problems dealing with this matter. Couples may face issues as to communicating with each other about changes in their sexual relationship, which may lead to marital dissatisfaction and a further decrease of the intimate relationship (33).

Although great part of the couples in this study experienced no impact of sexual side effects on their relationship, still a third of them encountered negative impact. Healthcare providers should be aware of the fact that providing sexual health care

does not only consist of carrying out treatments for ED, yet also of preventing relational issues caused by these side effects. It is of the utmost importance to not only focus on regaining erectile function, but to also aim at enhancing intimacy and the sexual relationship between men and their partners, whereas sexual health of the partner should not be neglected. A medical professional may not always be the most indicated person to provide this kind of health care, due to lack of time, knowledge or competence (34, 35). Guidance in intimacy and relational matters may be more adequate when provided by a sexologist or a psychologist specialized in sexology.

One of the strengths of this study is that partners could be paired to the patients in order to investigate if clinical characteristics were associated with the extent of how difficult partners found it to deal with treatment-related sexual side effects and how much problems the experienced with sexuality. Moreover, privacy of both patient and partner was guaranteed considering the questionnaires were sent separately.

Limitations included the fact that certain data of patients remained unknown, such as length of relationship in years and clinical characteristics, due to lack of informed consent. No validated questionnaires were used. The retrospective aspect of this cross-sectional design may have led to imprecise answers, since men had to report degree of erectile complaints and sexual activity in hindsight. The response rate of partners could not be established since it was beyond the bounds of possibility to determine the exact number of men in a relationship beforehand. Since it concerned a questionnaire with delicate questions, the survey could have led to sociably desired answers, despite anonymity was ensured. We excluded homosexual partners, since the number of homosexual participants was limited. It is likely that differences in sexual orientation may lead to different responses. Hence, this matter should be investigated as a separate subject in future research.

Conclusions

More than half of the partners of men with an increase in erectile complaints after PCa treatment found it difficult to deal with treatment-related sexual side effects and experienced sexual problems. Partners with a lower educational level experienced less sexual problems, whereas partners of men surgically treated or with IMRT experienced more sexual problems. Discrepancies between men and partners concerning treatment-related sexual side effects were identified: although men reported no increase in erectile complaints, their partners found it difficult to deal with sexual side effects and experienced sexual problems. Overall, the majority of men and partners indicated to not have experienced impact of sexual side effects on their relationship.

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Chapter 5

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