Sexual Functioning among Young Adult Cancer Patients: A 2-Year Longitudinal Study

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Condensed Abstract: More than half of participants reported problems with sexual functioning at each assessment and increased probabilities of reporting sexual dysfunction were observed over time and for YA cancer patients who were female, in a relationship, treated with chemotherapy, and reporting comorbid psychological distress and lower social support. For women, being in a relationship increased the likelihood of reporting sexual problems over time; for men reporting sexual problems over time increased regardless of relationship status.



Abstract

Background

Cancer-related sexual dysfunction has been reported among adolescents and young adults; however its prevalence over time has not. This longitudinal study investigated sexual dysfunction in AYAs over two years following initial diagnosis.

Methods

Young adult (YA) patients (18-39 years) completed the MOS Sexual Functioning Scale within the first 4 months of diagnosis (n=123), and again 6 (n=107) and 24 months later (n=95). An ordered multinomial response model analyzed changes in the probability of reporting sexual dysfunction over time and the independent effects of demographic, clinical, and psychosocial variables.

Results

More than half of participants experienced sexual functioning to be problematic at each assessment. The probability of reporting sexual dysfunction increased over time (<.01) and was greater for cancer patients who were female (<.001), older (<.01), married or in a committed relationship (<.001), treated with chemotherapy (<.05), and reporting comorbid psychological distress (<.001) and lower social support (<.05). For women, being in a relationship increased the likelihood of reporting sexual problems over time; for men reporting sexual problems over time increased regardless of relationship status.

Conclusions

A substantial proportion of YAs report on-going problems with sexual functioning in the first two years following their cancer diagnosis. These findings justify the need to evaluate and monitor sexual functioning throughout a continuum of care.

Keywords: cancer, sexual functioning, AYA, adolescents, young adults



INTRODUCTION

Adolescents and young adults (AYAs) with cancer, as defined by the National Cancer Institute, are individuals between 15 and 39 years of age at diagnosis. Considerable research has unveiled unique challenges experienced by AYAs, including poor quality of life, altered body image, and social isolation. As a consequence of these life disruptions, normative psychological and emotional development is impacted by the disease and its treatment, particularly with regard to sexual identity, development, and behavior. However, few studies have examined sexual functioning and AYA patients' needs with regard to emotional intimacy and sexual relationships. 6-8

Cancer symptoms and treatment-related physical difficulties affect a healthy sexual development among AYAs.^{6, 9.} Nerve damage can cause erectile and ejaculatory dysfunction, reduce sexual desire, and impair the ability to reach orgasm in both men and women.¹⁰ Younger women may be particularly vulnerable to the physiological effects of chemotherapy, which often induces early menopause, vaginal dryness, and dyspareunia.¹¹ Estimates of the prevalence of sexual dysfunction in AYAs are limited to date and vary due to data being derived from mixedage groups, single items instead of standardized instruments, and cross-sectional designs.⁷ Yet, the state of the science suggests that one-third to two-thirds of cancer patients experience sexual dissatisfaction and reduced frequency of intercourse.^{4, 6, 7} One prior study reported that at 1 and 2 years post-diagnosis, prevalence of sexual problems for AYAs was 49% and 43% respectively.⁷ Correlates of sexual problems include age, gender, relationship status, physical function, body image, and health-related quality of life.^{6, 7, 12}

Sexual dysfunction describes a disorder that affects one or more phases of the human sexual response cycle, ¹³ potentially leading to psychological and relational distress. ¹⁴ Integrative

models of sexuality that consider relational, psychological, cultural, and physiologic aspects have emerged in cancer survivorship and direct this work. ^{10, 13} While prevalence rates of sexual problems have been reported for 30-50% of healthy adults ¹⁵ and 44-57% of healthy adolescents, ^{16, 17} recent research suggests that the implications of sexual dysfunction for young people diagnosed with cancer in their teenage and young adult years are different from those of healthy peers, childhood cancer survivors, and adult cancer patients. AYAs are more likely to enter committed partnerships and to start a family while facing cancer. ^{6, 7} Furthermore, failure to address sexual health may place AYAs at risk for long term consequences related to sexual functioning and identity development, ¹⁸ interpersonal relationships, ⁴ and quality of life. ¹⁹ As such, detecting changes in the rate of sexual dysfunction over time may help in identifying appropriate timing for interventions to be delivered. The present work extends current knowledge of sexual functioning among AYAs by examining the prevalence of sexual dysfunction over two years following initial cancer diagnosis. It also aims to identify variables that contribute to sexual dysfunction in order to recognize individuals at higher risk.

MATERIALS AND METHODS

This study is part of a larger multisite longitudinal investigation of psychosocial outcomes in a national sample of AYAs, with study details reported elsewhere.²⁰ Institutional Review Board approval was obtained at the coordinating center and from each participating site.

Sample and Procedure

Serial recruitment over two years (2008-2010) involved identifying young people treated at three children's hospitals and two university-affiliated adult medical institutions in California, Oregon, and Texas, age 14-39 years, first diagnosis with any invasive cancer, and able to read and understand English or Spanish. Data were collected within 4 months from diagnosis, and

again 6 and 24 months later. Young adult (YA) patients (≥ 18.y.o.) were administered the sexual functioning scale as part of the survey, and only those who completed the instrument at least once were included in this analysis. Hence, 123 participants comprised the baseline sample. Five participants died between the first and the second assessment, and complete data were available for 107 patients at the 6 month follow-up (13% attrition rate). When the survey was administered again 2 years after baseline, 12 patients were deceased and 95 returned the materials (22.7% attrition rate).

Measures

Sexual Functioning was measured with the MOS Sexual Functioning Scale,²¹ a validated instrument used to identify sexual impairment accompanying serious health conditions. Four items assess the individual's ability to be interested in sex and to achieve sexual arousal and orgasm. The scale is sensitive to gender differences, with two separate versions for males and females. Items are measured on a Likert scale ranging from 1 = "not a problem" to 4= "very much a problem." A fifth response category ("not applicable") indicates that the respondent is not sexually active, and is recorded as "not a problem" according to manualized scoring instructions.²² The total score is obtained for males and females by averaging the sum of the items and then transforming the scores on a 0-100 scale, with higher scores indicating more impairment. Cronbach's alpha was .90 and .92 for men and women.²¹

Psychological Distress. The Brief Symptom Inventory-18 (BSI-18) is a well-established instrument to screen for psychological distress.^{23, 24} It contains 18 items organized into three subscales (depression, somatization, anxiety) and a summarized Global Symptom Index (GSI). A five-point Likert scale (ranging from 0='not at all' to 4='extreme') measures the extent to which a respondent has experienced distress over the past week. Raw scores are converted to age- and

gender-adjusted T-scores for comparison to community norms (mean=50, SD=10), with higher scores indicating greater distress. A GSI score ≥ 63 suggests clinical distress and need for assessment. Cronbach's alpha was .95 in the original study.²³

Health-Related Quality of Life. The Short Form 36 (SF-36) assesses health-related quality of life. ²⁵ The instrument includes eight subscales: physical functioning, physical and emotional role limitations, bodily pain, social functioning, mental health, vitality, and general health perceptions. Subscale scores are standardized and then aggregated in a Physical and a Mental Component Score, with higher scores indicative of better functioning. Data for summary scales are presented as T-scores (mean =50, SD=10). Cronbach's alpha was .90. ²⁵

Social Support. Social support was investigated with the MOS Social Support Survey.²⁶ It is a questionnaire composed of 19 items that used 5 response categories. Scores are calculated for five functional support scales and an overall social support index, with higher scores indicating greater social support. Only the total score was included in the analysis. Cronbach's alpha of the original scale was higher than .90.²⁶

Demographic and clinical characteristics. Demographic measures, including gender, race, education, income, employment, and relationship status were self-reported. Clinical data obtained from medical records comprised of age at diagnosis, cancer types and treatment. Three categories of severity were created from Surveillance Epidemiology and End Results (SEER) codes: (1) diseases with expected five-year survival rates greater than 80%; (2) diseases with expected five-year survival rates between 50-80%; and (3) all other invasive malignancies with expected five-year survival rates less than 50%.

Data analysis

Descriptive statistics summarized the sample at each time point. Then, single item frequencies for sexual functioning by gender were computed (see Additional Materials). Due to the non normal distribution of the mean score of the outcome variable, a nonlinear analysis using an ordered multinomial response model with a log-link function was implemented to analyze changes in the probability of reporting sexual dysfunction over time, treating the outcome variable as ordinal. Respondents with a total sexual function score ≤ 25 were assigned "not a problem," those with scores ranging from 26-50 were assigned "a little of a problem," those with score ranging from 51-75 were assigned "somewhat of a problem," and those with scores \geq 76 were assigned "very much of a problem." Hierarchical generalized linear modeling (HGLM) with backward selection method allowed to identify patterns within (level 1) and between (level 2) individuals, as well as for testing potential interactions.²⁷ Model fit was accomplished with Bayesian modeling using Markov Chain Monte Carlo (MCMC) estimation, ²⁸ with MLwiN. version 2.24.²⁹ Continuous variables were grand mean-centered, to control for potentially problematic correlations among random components³⁰. The model was allowed to vary on the intercept (level 2). The distribution of each variable, including outliers, was inspected and corrected to prevent any violation of functional form. No missing data existed for the second and third survey time point on the outcome measure.

At level 1, the outcome variable differs over time within individuals and it is a function of time and individual-specific change parameters. At level 2, individual-specific change parameters are considered to vary between subjects and are modeled as a function of variables differing between individuals. Time variant variables within patients (level 1) included relationship status, employment, treatment type, psychological distress, summary measures of physical and mental health, and social support. Time invariant variables (level 2) included sex,

race, education, age at diagnosis, and severity of disease. Model-fit was accomplished by first estimating the unconditional means model (Model A) that simply described and partitioned the outcome variation. Time was then added to estimate the unconditional growth model (Model B), where change in the outcome variable was described over time. Then the conditional growth model with time invariant and time variant main effects was estimated (Model C), and finally the conditional growth model with main and interaction effects (Model D).

RESULTS

Demographic, clinical, and psychological measures are summarized in Table 1. Participants were mostly men (53.7%), Non-Hispanic white (53.3%), diagnosed with cancer in their late 20s (mean 28.2), and had received treatment including chemotherapy (72.1%). At baseline most AYAs were involved in a romantic relationship (58.7%). At the 6 months follow-up the proportion declined to 40% and at 2 years post-diagnosis 43.2% of participants were partnered. Psychological distress increased over time, with the mean GSI score ranging from 57.1 at baseline to 68.3 at the last follow-up. Both physical and mental components of health-related quality of life improved over time; however they remained below the standardized population mean. Rates of social support remained elevated over time.

At baseline and six month follow-up, more than half of all YA patients (52% and 54.2% respectively) reported some degree of problem with sexual functioning. After 2 years more than half (52.1%) of the sample still reported some degree of affected sexual functioning (Table 2). Results of the ordered multinomial response model (Table 3) indicate that increased probabilities of sexual dysfunction were reported over time (p<.01). In this sample, a significant main effect of gender was detected, with women presenting higher likelihood of reporting sexual problems than men (p<.001). Worse sexual functioning was predicted for older cancer patients (p<.01),

with young adults at the 90th percentile of age (approximately 38 years) more likely to report sexual dysfunction than younger participants (10th percentile, 19 years). Additionally, YAs who were involved in a relationship with a partner were estimated to have higher probabilities of experiencing sexual dysfunction (p<.001). Among clinical factors, cancer patients who received chemotherapy had an increased chance of sexual problems (p<.05). Higher psychological distress was significantly associated with increased probabilities of sexual dysfunction (p<.001). On the contrary, social support was predictive of reduced likelihood of sexual problems (p<.05). Finally, two significant interactions were identified: a two-way interaction of cancer survival by gender (p < .01), and a three-way interaction of time by gender and relationship status (p < .05). While among women with higher survival rates the probabilities of reporting sexual functioning as problematic were similar, worse sexual outcomes were predicted for those with a survival rate less than 50% (Figure 1). For males probabilities were similar across the three groups. Figure 2 presents the predicted probabilities of sexual dysfunction over time for the two genders by relationship status. For women, being in a relationship increased the likelihood of reporting sexual problems over time than not-partnered females; for men reporting sexual problems over time increased regardless of relationship status.

DISCUSSION

Following earlier research indicating that 43% of patients reported affected sexual life 2 years post-diagnosis,⁷ the current study provides further evidence that substantial portions of YAs continue to struggle with sexual functioning over time. Rates of sexual dysfunction observed here are consistent with those found in other studies. Among male survivors of lymphoma, sexual dysfunction ranged from 20% to 54% across studies³¹, while for testicular cancer patients the percentages varied from 11% for loss of desire to 51% for ejaculation

problems.³² Up to 52% of young breast cancer patients were found to experience sexual problems³³ and to present poorer sexual function compared to both older survivors and agematched control groups.³⁴ In a cross-sectional study of sexual satisfaction and quality of close relationships among young German patients, one-third of the sample was not satisfied with sexual life and frequency of intercourse.⁶ However, our participants reported higher prevalence than those in the work by Wettergren et al.;⁷ a result which may be partially explained by the different measures (dichotomous item vs. questionnaire). The MOS Sexual Functioning scale has been previously used in cross-sectional studies to assess sexual problems in childhood cancer survivors ³⁵ and validated with adults faced with medical conditions.²² Our participants reported greater prevalence of sexual dysfunction than childhood cancer survivors (42.7%), however in the validation study of the scale 59% of the sample reported sexual problems²¹. Despite these differences, our results confirm that sexual functioning of young adults is significantly affected by cancer, with implications for the well-being of the individual that extend beyond active treatment.

Female gender was associated with higher probabilities of sexual dysfunction, especially for those with a survival rate less than 50%. Although a few studies have analyzed gender differences in the presentation of sexual dysfunction among AYAs, the worse outcomes observed for women are consistent with data from existing literature. Notably, a study revealed that more than 70% of young female survivors experience reduced frequency of sexual intercourse after diagnosis. Our findings are also similar to the work of Champion et al., who identified a pattern of decreased interest, arousal, and frequency of orgasm. Sexual difficulties in young women begin after surgery, and although for some they gradually decrease, sexual functioning remains problematic one and five years the sexual difficulties.

The probability of sexual problems increased over time for all YAs; however when accounting for relationship status sexual problems worsened for women who were married or in a relationship, whereas for men sexual dysfunction worsened regardless of their relationship status, suggesting that sexual functioning is experienced differently by gender. While results confirm that sexual problems are reported by cancer patients involved in a relationship, ^{12, 35} the diverging trends for women and men not in a relationship direct the attention toward male patients, as this group may be at higher risk for long-term sexual problems. Our finding reflects the complexity of adjusting and coping with cancer as a young adult and recommend additional research to examine the differential effects of cancer on sex and sexuality for men, women, and transgender young people.

Older age, chemotherapy, and psychological distress were predictive of the probability of reporting sexual dysfunction while social support had a protective effect in this sample. Worse outcomes for young adults confirm the more detrimental effect of cancer on their sexual functioning.⁷ Similarly, previous linkage of chemotherapy with sexual dysfunction, ⁴¹ either directly or because of treatment- related consequences, was confirmed. ⁴² Future research is needed to determine the extent to which biological, neurological, and psychological mechanisms interact in this population. YAs reporting high psychological distress had greater probabilities of worse sexual functioning ^{12, 43, 44} but no significant role was played by health-related quality of life; a lack of significance similar to results from the AYA HOPE study. ⁷ Finally, the relevance of supportive networks for this group ⁹ is represented by the result for perceived social support.

Some limitations affect the current study. First, more frequent assessments would have provided more accurate estimates of sexual dysfunction. Second, the MOS Sexual Functioning Scale focuses on performance indicators but excludes satisfaction with sexuality and associated

distress. Since addressing sexual problems in the context of cancer requires an integrative approach, ¹⁰ a multi-dimensional measure should have been considered. Attrition rates confirm the challenges of recruiting and following-up with AYAs. ⁴⁵ Studies that actively promote subject retention are needed. Finally, the study did not include a matched-control group, and therefore lacks the ability to compare current findings with normative data.

Approximately half of YA cancer patients experienced some degree of sexual dysfunction for up to two years post-diagnosis, which reached moderate-to-severe levels for nearly one-quarter of the sample. Time, demographic, clinical, and psychosocial variables contributed to reporting sexual problems. Embarrassment and limited training among providers have contributed to the current lack of attention for sexual dysfunction among AYAs. This study emphasizes the need to implement protocols that monitor sexual functioning throughout a continuum of care and connect patients to psychosocial interventions that alleviate the life disruptions caused by cancer and its treatment.



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Table 1. Sample demographic, clinical, and psychosocial characteristics

		N (%)	
Characteristics	Baseline	6 months Follow-Up	24 months Follow-Up
	(N=123)	(N=107)	(N=95)
Demographic Characteristics			
Gender M.L.	(((52.70/)		
Male	66(53.7%)		
Female	57(46.3%)		
Relationship Status Yes	71(58.7%)	42(40.0%)	41(43.2%)
No	50(41.3%)	63(60.0%)	50(52.6%)
Race*	30(41.370)	03(00.070)	30(32.070)
Non-Hispanic White	65(53.3%)		
Hispanic/Latino	43(35.2%)		
Others	14(11.5%)		
Education*	- 1(10-7-0)		
High School or less	46(37.7%)		
Some college or more	77(62.3%)		
Income*	,		
Under \$25,000	58(47.9%)		
Above \$25,001	63(52.1%)		
Employment/School status			
Not Occupied	71(59.7%)	53(51.0%)	37(39.8%)
Occupied	48(40.3%)	51(49.0%)	56(60.2%)
Clinical Factors			
Age at Diagnosis, Mean (SD)	28.2(7.1)		
Age at Diagnosis (Categorical)			
18-25 years	43(35.0%)		
26-39 years	80(65.0%)		
Type of Cancer (% of survival)*	22(2(.00/.)		
< 50%	32(26.0%)		
50-80% 80-100%	49(39.8%)		
	42(34.1%)		
<u>Cancer Type[*]</u> Leukemia	19(15.6%)		
Breast	18(14.8%)		
Soft Tissue Sarcoma	15(12.3%)		
NHL	13(10.7%)		
Bone	10(8.2%)		
Testicular	10(8.2%)		
Hodgkin's Disease	9(7.4%)		
Female Genital	7(5.7%)		
Brain	6(4.9%)		
Other	15(12.2%)		
<u> reatment</u>	,		
Chemotherapy	88(72.1%)	42(39.3%)	24(25.5%)
Radiation	23(18.9%)	3(2.8%)	· – ´
Surgery	30(24.6%)	12(14.0%)	22(23.4%)
Psychosocial Variables			
Psychological Distress			
GSI Mean (SD)	57.1(10.8)	55.1 (11.2)	68.3(5.8)
Range	33.0-81.0	33.0-81.0	61.0-81.0

Quality of Life			
SF36 Physical Component	39.9(10.4)	39.6(10.5)	40.1(10.1)
Mean (SD)			
Range	13.7-59.6	13.8-62.0	13.7-61.9
SF36 Mental Component	40.8(13.6)	43.0(13.0)	44.2(11.1)
Mean (SD)			
Range	8.0-67.2	9.9-67.2	18.2-63.8
Social Support			
MOS Social Support Overall Index	4.2(.9)	4.2(.9)	4.0(1.2)
(mean score)			
Range	1.0-5.0	1.0-5.0	1.0-5.0
*Variable measured only at baseline			
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Table 2. Sexual functioning groups obtained from the total scores on the MOS Sexual Functioning Scale



Table 3. Multilevel models predicting the probability of reporting sexual dysfunction over time (n=325)

MODEL A	MODEL B	MODEL C	MODEL D
			1.44(0.7)*
			3.04(0.7)***
2.59(0.3)***	2.95(0.5)***	3.23(0.7)***	4.49(0.8)***
	-0.16(0.1)	-0.42(0.2)* -0.33(0.4) -0.08(0.1)** 1.15(0.3)*** -0.67(0.3)* -0.06(0.1)*** 0.42(0.2)* 0.60(0.5) 0.53(0.5)	-0.50(0.2)** -2.51(0.7)*** -0.07(0.1)** 0.68(0.4) -0.73(0.3)* -0.06(0.1)*** 0.37(0.2)* -0.60(0.6) -0.63(0.6) 2.36(0.8)** 2.44(0.9)** 0.48(0.2)*
2.7(0.8)	2.0(0.0)	2.4(0.0)	2.1(0.9)
2.7(0.8)	2.9(0.9)	2.4(0.9)	2.1(0.8)
757 9	757 9	721 3	717.9
			82.1
			154
			325
975	975	975	975
	-0.09(0.2) 1.32(0.2)*** 2.59(0.3)*** 2.7(0.8) 757.9 89.9 154 325	-0.09(0.2)	$\begin{array}{cccccccccccccccccccccccccccccccccccc$

^{*}p < .05 **p < .01 *** p < .001

Figure Legends:

Figure 1. Predicted probabilities of reporting sexual dysfunction by survival for the two genders

Figure 2. Predicted probabilities of reporting sexual dysfunction by gender and relationship status



Page 25 of 27 Cancer

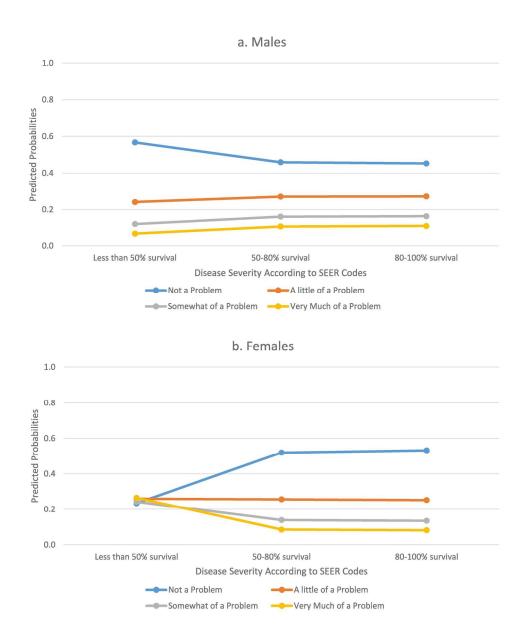


Figure 1. Predicted probabilities of reporting sexual dysfunction by survival for the two genders $203x239mm (300 \times 300 DPI)$

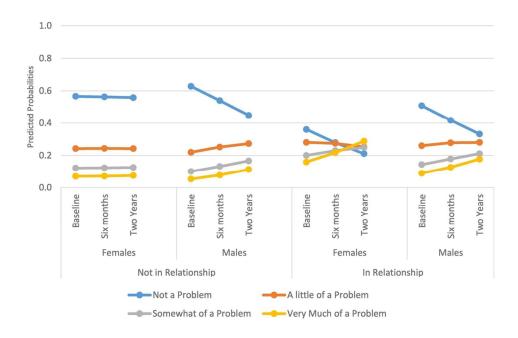


Figure 2. Predicted probabilities of reporting sexual dysfunction by gender and relationship status $99x62mm (300 \times 300 DPI)$

Table S1. Descriptive statistics for MOS Sexual Functioning Scale by gender

	N (%)				
	Baseline	6 Months	24 Months Follow-Up		
		Follow-Up			
	(N=123)	(N=107)	(N=95)		
Item 1-Lack of Sexual Interest					
<u>Men</u>					
Not a problem	44(66.7%)	42(73.7%)	32(62.7%)		
A little of a Problem	8(12.1%)	5(8.8%)	11(21.6%)		
Somewhat of a Problem	10(15.2%)	7(12.3%)	5(9.8%)		
Very Much of a Problem	4(6.1%)	3(5.3%)	3(5.9%)		
<u>Women</u>					
Not a problem	28(49.1%)	26(52%)	21(47.7%)		
A little of a Problem	11(19.3%)	9(18.0%)	9(20.5%)		
Somewhat of a Problem	5(8.8%)	7(4.5%)	5(11.4%)		
Very Much of a Problem	13(22.9%)	8(16.0%)	9(20.5%)		
Item 2-Unable to Relax and Enjoy Sex					
Men Not a problem	10(60, 60/.)	40(70, 20/)	31(60.99/)		
A little of a Problem	40(60.6%) 9(13.6%)	40(70.2%)	31(60.8%) 7(13.7%)		
Somewhat of a Problem	11(16.7%)	7(12.3%) 6(10.5%)	10(19.6%)		
-					
Very Much of a Problem	6(9.1%)	4(7.0%)	3(5.9%)		
Women Not a problem	35(61.4%)	28(56.0%)	25(56.8%)		
A little of a Problem	9(15.8%)				
Somewhat of a Problem	5(8.8%)	10(20.0%) 7(14.0%)	6(13.6%)		
	8(14.0%)	` '	5(11.4%)		
Very Much of a Problem	0(14.070)	5(10%)	8(18.2%)		
Item 3-Difficulty in becoming Sexually Aroused					
Men					
Not a problem	49(74.2%)	39(68.4%)	36(70.6%)		
A little of a Problem	8(12.1%)	11(19.3%)	6(11.8%)		
Somewhat of a Problem	5(7.6%)	4(7.0%)	5(9.8%)		
Very Much of a Problem	4(6.1%)	3(5.3%)	4(7.8%)		
Women	1(0.170)	3(3.370)	1(7.070)		
Not a problem	38(66.7%)	28(56.0%)	22(50.0%)		
A little of a Problem	6(10.5%)	9(18.0%)	8(18.2%)		
Somewhat of a Problem	4(7.0%)	8(16.0%)	6(13.6%)		
Very Much of a Problem	9(15.8%)	5(10.0%)	8(18.2%)		
Item 4-Difficulty in getting or keeping an	,	/	,		
erection (Men); Difficulty having an					
orgasm (Women)					
<u>Men</u>					
Not a problem	49(74.2%)	40(70.2%)	36(70.6%)		
A little of a Problem	8(12.1%)	9(15.8%)	7(13.7%)		
Somewhat of a Problem	7(10.6%)	4(7.0%)	2(3.9%)		
Very Much of a Problem	2(3.0%)	4(7.0%)	6(11.8%)		
<u>Women</u>					
Not a problem	37(64.0%)	29(58.0%)	23(52.3%)		
A little of a Problem	10(17.5%)	11(22.0%)	9(20.5%)		
Somewhat of a Problem	3(5.3%)	5(10.0%)	7(15.9%)		
Very Much of a Problem	7(12.3%)	5(10.0%)	5(11.4%)		