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Psychological Correlates of Sexual Dysfunction in Female Rectal and Anal Cancer Survivors: Analysis of Baseline Intervention Data

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Abstract

Introduction—Sexual dysfunction represents a complex and multifactorial construct that can affect both men and women and has been noted to often deteriorate significantly after treatment for rectal and anal cancer. Despite this, it remains an understudied, underreported and undertreated issue in the field of cancer survivorship.

Aim—This study examined the characteristics of women enrolled in an intervention trial to treat sexual dysfunction, and explored the relationship between sexual functioning and psychological well-being.

Main Outcomes Measures—Quality of life (EORTC-QLQ-C30 & QLQ-CR38), sexual functioning (FSFI) and psychological well-being (BSI Depression/Anxiety, IES-R, CR-38 Body Image).

Methods—There were 70 female post-treatment anal or rectal cancer survivors assessed as part of the current study. Participants were enrolled in a randomized intervention trial to treat sexual dysfunction and completed outcome measures prior to randomization.

Results—Women enrolled in the study intervention were on average 55 years old, predominantly Caucasian (79%), married (57%) and a median of 4 years post-primary treatment. For those reporting sexual activity at baseline ($N=41$), sexual dysfunction was associated with a range of specific measures of psychological well-being, all in the hypothesized direction. The Sexual/Relationship Satisfaction subscale was associated with all measures of psychological well-being ($r=-.45$ to $-.70$, all $p<.01$). Body image, anxiety and cancer-specific post-traumatic distress were notable in their association with subscales of sexual functioning, while a global quality of life measure was largely unrelated.

CONFLICT OF INTEREST:

None

Conclusions—For sexually-active female rectal and anal cancer survivors enrolled in a sexual health intervention, sexual dysfunction was significantly and consistently associated with specific measures of psychological well-being, most notably Sexual/Relationship Satisfaction. These results suggest that sexual functioning may require focused assessment by providers, beyond broad quality of life assessments, and that attention to Sexual/Relationship Satisfaction may be critical in the development and implementation of interventions for this cohort of patients.

Keywords

Sexual Dysfunction; Sexual Health; Rectal Cancer; Psychological Distress

Introduction

Approximately 46,000 Americans will be diagnosed with rectal or anal cancer in 2012 [1]. Improvements in detection and treatment have resulted in increased survival rates for this patient population and thus post-treatment functioning has become an increasingly important domain of enquiry [1, 2]. Treatment for rectal and anal cancer can involve a combination of radiation, chemotherapy and surgery, and can involve the need for a permanent or temporary stoma. These treatment modalities can result in significant morbidity, and can involve alterations to gastrointestinal, bowel, bladder and sexual functioning [3, 4]. Despite this, sexual dysfunction remains understudied, is rarely discussed pre-operatively, and evidence-based interventions are lacking [5–7].

Sexual dysfunction represents a complex and multifactorial construct that can affect women and has been noted to deteriorate significantly after treatment for rectal cancer [e.g. 8, 9–17]. In a study of 200 rectal cancer long-term survivors, Hendren and colleagues [11] found that a significant number of females (29%) reported surgery to have negatively impacted their sexual functioning, frequently endorsing problems associated with lubrication (56%), pain during sexual activity (46%) and low desire (41%). Despite these high levels of endorsement, very few participants were able to recall discussions of sexual functioning with their health care provider or undertook any form of treatment. In comprehensive reviews of the literature [3, 18], reported rates of sexual dysfunction in female post-treatment rectal cancer patients were found to be significant but imprecise, ranging from 19–62% across the reviewed studies. Whereas fewer studies exist of post-treatment sexual function in anal cancer patients, published reports have noted impairment in this domain [4, 19, 20].

The relationship between female sexual dysfunction, patient reported quality of life and distress remains complex and not well understood. In a long-term prospective study of rectal cancer patients, Engel and colleagues [21] reported that, while quality of life and functioning scores improved over the course of the four year study, they remained below those of the general population. Importantly, sexual functioning scores did not follow this trajectory and remained low throughout the study, thus indicating a degree of independence from multifaceted domains of quality of life. Further studies have reported mixed results regarding the relationship between quality of life and sexual dysfunction in patients diagnosed with colorectal, rectal and anal cancer. [4, 9, 10, 20, 22–28].

Although quality of life measures provide a broad assessment of functioning, there exists a paucity of research pertaining to the relationship between sexual dysfunction and more focused measures of psychological well-being. Studies of the experience of breast and gynecological cancer survivors have documented an association between sexual dysfunction and impairments in body image and relationship quality, distress, depression and anxiety

[29–35], while in contrast Onujiogu and colleagues [36] reported no relationship between sexual functioning and depression in a study of women with early stage endometrial cancer.

Aims

Post-treatment sexual dysfunction may be associated with impaired psychological well-being, yet this relationship remains to be fully elucidated in anal and rectal cancer survivors. An enhanced understanding of sexual dysfunction and its psychological correlates is important in identifying patients in need of assistance and in the development and implementation of effective interventions. The conceptual framework for this study was to describe the clinical and psychosocial characteristics of women diagnosed with rectal or anal cancer that enrolled in a sexual health intervention, with consideration of the relationship between demographic and medical characteristics and study outcomes. A subgroup analysis of women reporting sexual activity at the beginning of the intervention was also conducted to further characterize this cohort. The results of these analyses are discussed in the context of care, and attention given to future research. It was hypothesized that sexual dysfunction would be significantly and inversely associated with specific measures of psychological well-being in sexually active participants.

Methods

Participants

There were 278 eligible women approached by research staff in person or by mail for study participation. Of these women, 105 declined (53% of eligible respondents), 59 did not respond, and 20 were found ineligible after further discussion. Inclusion criteria included; (1) being post-treatment (post radiation and/or surgery for stage I-III rectal adenocarcinoma or rectosigmoid cancer with an anastomosis at 15cm or below, post radiation and/or chemotherapy for anal cancer), (2) no evidence of disease, (3) at least 21 years old, (4) able to communicate proficiently in English, (5) no significant cognitive or psychiatric disturbance, and (6) reported less than or equal to moderate satisfaction with their overall sexual life. Ninety-four eligible women were consented for the study intervention; however 24 were deemed ineligible after consent or dropped out prior to completing the baseline assessment. The characteristics of the 70 women with completed baseline questionnaires are presented.

Main Outcome Measures

Medical and Socio-demographic Information—Each participant provided demographic data including; race, education level, age, employment status, occupation, and marital/partner status. Medical and treatment data (e.g., time since treatment, surgical factors (i.e. anastomosis, type of reconstruction, placement of ostomy)) was collected by medical chart review.

Female Sexual Functioning Index [FSFI; 37]—The FSFI is a 19-item self-report measure of sexual function rated on a five or six-point Likert scale and based on the past four weeks. This measure addresses six domains of sexual functioning: 1) Desire, 2) Arousal, 3) Lubrication, 4) Orgasm, 5) Satisfaction, and 6) Pain/discomfort. For the current study, the satisfaction domain is referred to as Sexual/Relationship Satisfaction to provide greater clarity. Internal reliability coefficients for the FSFI in the current study ranged from 0.76 to 0.96.

Impact of Events Scale-Revised [IES-R; 38]—The IES-R is a measure that has been previously employed in cancer settings to detect cancer-related distress [e.g. 39]. This

measure assesses an individual's subjective response to an identified trauma (i.e. cancer) through the administration of a 22 item self-report measure. Items assess symptoms associated with hyperarousal, intrusive thoughts and avoidance on a five point Likert scale based on the past seven days. The internal reliability coefficient for the total score was .93 in the current study, with the three subscales ranging from 0.82 to 0.85.

The Brief Symptom Inventory [BSI; 40]—The BSI consists of 53 self-report items that participants respond to on a five point Likert scale based on their experience during the past month. Questions form nine symptom dimensions; however for the purpose of the current study, only the Depression and Anxiety subscales were examined. The internal reliability coefficient for these scales in the current study was 0.87 and 0.77 respectively.

European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire [EORTC-QLQ-C30; 41] and Colorectal Cancer-Specific Module [EORTC-QLQ-CR38; 42]—The EORTC-QLQ-C30 is a 30-item self-report measure used to assess health-related quality of life in cancer patients. Based on the past seven days, participants respond to questions on a four point Likert scale, with the exception of two questions that are rated from one to seven to form the Global Health Status subscale. The Global and Emotional Functioning subscales were used due to their relevance to the current study with internal reliability coefficients noted as 0.87 and 0.85 respectively. The EORTC-QLQ-CR38 assesses quality of life domains specific to colon cancer as a supplement to the core EORTC-QLQ-C30 questionnaire. It consists of 38 self-report items rated on a four point Likert scale and based on the past week (or four weeks for sexual functioning questions). The subscales assessing Body Image, Sexual Enjoyment and Sexual Functioning were examined for this study with internal reliability coefficients of 0.88 (Body Image) and 0.67 (Sexual Functioning).

Procedure

The majority of patients were approached in-clinic or by letter cosigned by the principal investigator and their treating physician and including a study brochure and consent form. Individuals who did not respond to the letter were contacted by telephone or sent a follow-up letter requesting that they contact research staff if they were interested in participating in the study. A manualized sexual health intervention developed by authors JC, LS, LT and KD through clinical experience, prior research and a thorough literature review was used in the study.

Statistical Analysis

Descriptive analyses were conducted to examine departures from normality and evidence of non-random missing data. For missing data that was random and minimal, a mean substitution method was employed where appropriate. Descriptive analyses were conducted to examine means and standard deviations of study measures, while independent t-test and chi-square analyses were used to explore the relationship between marital status, sexual activity, time since treatment and study variables (relevant demographics (age, cancer type), measures of psychological well-being). Bivariate correlations were conducted to examine the relationship between the FSFI and measures of psychological well-being in sexually active participants. For 15 of the 19 questions respondents can report 'no sexual activity', which has raised concern regarding the validity of the FSFI in assessing women who are non-sexually active [43, 44]. Based on recommendations from a previously published validation study of the FSFI, analyses for this scale were reported for sexually active women only, defined as women who indicated no sexual activity/intercourse or had a missing response to fewer than 8 of the 15 questions [45]. Finally, exploratory analyses were conducted in order to elucidate possible predictors of sexual functioning in this subgroup.

Since the psychological variables are all correlated, and we wanted to retain at least ten subjects for each variable, the psychological well-being variable with the highest correlation with sexual functioning (FSFI Total) was identified and entered into the analysis, controlling for marital status, age and time since treatment.

Results

The study sample included 70 women with a mean age of 55.43 years, the majority of whom were Caucasian (79%), married (57%), and employed (47%). At baseline, participants were on average 4.27 years (median=4) from time of primary treatment (surgery for rectal cancer patients and chemotherapy/radiation for anal cancer patients). Due to changes to the inclusion criteria during the course of the study, one individual with colon cancer was included. Demographic details are presented in Table 1.

Primary Analysis

There were no significant departures from normality across the variables examined, with the exception of the Lubrication subscale of the FSFI. This subscale appeared bimodal; however responses were evenly distributed across the high and low end of the measure and thus included in the consequent correlational analyses. Missing data was minimal (less than 1%) across individual items and thus a mean substitution method was employed, where appropriate, in calculating scale and subscale scores. Participants' baseline scores are displayed in Table 2.

The relationship between marital status, sexual activity, time since treatment and study variables were examined in this group. Of the entire sample ($n=70$), 40 reported being married or living with a partner, while 30 indicated being single, divorced or widowed. T-test and chi-square analyses (corrected degrees of freedom used in cases of equality of variances assumption violated) revealed few significant differences between these two groups (relationship vs. no relationship) across relevant demographic and study variables. Married or partnered women reported significantly less avoidance-related cancer distress on the IES Avoidance scale ($t(44.6)=-2.4, p<.05$) when compared to those who identified as single, divorced or widowed. The relationship between years since diagnosis and study variables was analyzed; however no significant associations were identified with the exception of age ($r=.28, p<.05$). Sexually active women ($n=41$) were more likely to report being married or living with a partner ($\chi^2(1)=5.02, p<.05$); no other differences across demographic variables were established. Measures of psychological well-being were found to be similar for both sexually active and inactive participants in this study. However, for the domain of Emotional Functioning, a significant difference was noted ($t(67.94)=2.63, p<.05$), with sexually active women reporting greater impairment on this specific domain of quality of life.

Subgroup Analysis of Sexually Active Participants

The FSFI is considered a valid measure for sexually active women, therefore bivariate correlations between subscales of the FSFI and psychological outcomes are presented for these women. Analysis revealed several significant correlations in the expected directions (Table 3). The Intrusion subscale and Total score of the IES-R were significantly and inversely associated with four of six FSFI domains, as was the Anxiety subscale of the BSI. Body Image was significantly and positively associated with all six domains of the FSFI. Further analysis revealed few significant associations between the Global quality of life (QOL) subscale of the EORTC-QLQ-C30 and sexual functioning. Finally, the Sexual/Relationship Satisfaction domain of the FSFI was associated with all study outcome measures. The EORTC-QLQ-CR-38 sexual enjoyment and dysfunction subscales were

highly correlated with the FSFI subscales and thus were omitted from Table 3. Finally, in exploratory analysis of predictors of sexual functioning, body image possessed the highest correlation with the FSFI Total score ($r = .56, p < .01$) and was therefore entered into the regression analysis. Results indicated that body image was a significant predictor of sexual functioning ($r = .63, p < .001$), after controlling for age, marital status and time since treatment.

Discussion

Sexual functioning in survivorship continues to be underreported and understudied, particularly in female anal and rectal cancer survivors. Survivors who enrolled in a sexual health intervention study were predominantly Caucasian, married, employed women in their mid-fifties. The median time since treatment was 4 years. For sexually active participants, sexual dysfunction, most notably Sexual/Relationship Satisfaction, was most consistently associated with specific measures of psychological well-being. Findings as a whole underscore the importance of assessing and treating sexual dysfunction post-cancer treatment, while interventions should ensure that appropriate attention is given to psychological constructs and satisfaction with sexual and relationship dynamics.

Primary Analysis

Our findings are consistent with investigations within other survivorship groups, with our cohort possessing comparable quality of life to rectal cancer survivors [46] and long-term survivors of breast cancer and colorectal cancer [47]. In terms of sexual functioning, our cohort reported greater impairment across all FSFI domains when compared to a group of breast cancer survivors [30]. It is acknowledged, however, that women enrolled in this study reported being, at most, moderately satisfied with their overall sexual life, and were willing to engage in an intervention targeting sexual dysfunction. Finally, Carter and colleagues [48] reported improved sexual functioning over the course of two years of follow-up in a group of early stage cervical cancer patients. Despite many women in the current study being even further beyond treatment than these cervical cancer patients, greater impairment in their sexual functioning was reported at study inclusion.

In order to further explore the characteristics of the current sample, a preliminary exploration of relationship status, time since treatment, sexual activity and psychological correlates was conducted. Those who identified as married or partnered were less likely to report avoidance-related cancer-specific distress. Sexual desire, enjoyment and function can all be intimately tied to an individual's current relationship status. Whereas information was not collected as to whether non-partnered women were currently seeking a relationship, and the exploratory nature of this finding must be clearly acknowledged given the grouping of single, widowed and divorced women, it is possible that for non-partnered women, sexuality may be viewed as a critical component of creating a new relationship, and thus may prompt anxiety or avoidance. Future research should seek to fully explicate the role of partner status and desire for new relationships within the context of cancer treatment and sexual dysfunction.

Subgroup Analysis of Sexually Active Participants

A significant and consistent relationship between domains of sexual function and several specific measures of psychological well-being was found. Further, when compared to non-sexually active women across the entire sample, those who were sexually active reported greater impairment on a specific measure of emotional functioning. Engagement in sexual activity after treatment for rectal or anal cancer may prompt reminders of not only an individual's cancer and its treatment, but consequent changes in physical functioning, body

image and self-esteem, thus exacerbating distress and impairment. Cancer can be traumatic experience for many patients, and may be associated with the presence of frequent reminders or intrusive thoughts, or avoidance of stimuli associated with their treatment or recovery [49]. This may suggest the need for post-traumatic avoidance or intrusion-based symptomatology to be addressed within the design of sexual function interventions for this cohort; however further investigation is needed at this time.

Sexual/Relationship Satisfaction was inversely associated with symptoms relating to post-traumatic cancer-specific distress, depression and anxiety, and positively associated with quality of life, emotional functioning and body image. Satisfaction based questions are more global in nature and assess participants' degree of satisfaction with their overall sexual life and relationship, rather than specific elements of sexual functioning. Consistent with our findings, Speer and colleagues identified relationship distress to be a significant predictor of sexual functioning in breast cancer survivors [30]. Juraskova, who employed a qualitative study design, noted the emergence of themes related to communication and intimacy as critical elements of sexual adjustment in endometrial and cervical cancer survivors [34], while Carter noted relationship quality to positively associated with sexual function in women diagnosed with endometrial cancer [50]. Further population-based research has noted relationship qualities, such as intimacy, to moderate the association between distress and sexual functioning in women [51]. This suggests that interventions targeting sexual functioning may need to more explicitly address aspects of relationship quality, when appropriate, in addition to physiologically-focused symptomatology (e.g. lubrication, orgasm, pain), in order to maximize potential benefits for rectal and anal cancer survivors. Future research may also explore whether positive appraisal of one's relationship could buffer against the impact of sexual difficulties, or whether poor relationship dynamics may be predictive of post-treatment distress in women experiencing sexual dysfunction.

Participants' self-reported body image was found to possess the strongest and most consistent association with the various domains of sexual functioning. This subscale assesses women's general level of satisfaction with their body, as well as whether their disease or treatment was associated with feeling less physically attractive or feminine. Our findings support previous research examining the negative impact of a cancer diagnosis and treatment on body image and its relationship to sexuality [52], in particular in breast cancer patients [53–56]. Further, Hendren and colleagues reported that over half of female participants treated for rectal cancer were ashamed of their bodies [11], but it is unclear of the role of having a stoma or suffering from fecal incontinence post treatment may have played for these women. Despite this, a recent review noted that among couple-based interventions targeting female post-cancer adjustment, few explicitly addressed body image concerns [57].

In order to assist in guiding future studies, as well as generating suggestive hypotheses, we conducted an exploratory analysis of predictors of sexual functioning amongst sexually active participants. Whereas the sample size of the current study precluded extensive investigation, and the results must be considered with caution, it was found that body image remained a significant predictor of sexual functioning, after controlling for relevant demographic and treatment variables. This preliminary finding, along with that noted above, support further investigation into this relationship and the possible association between body image concerns after cancer treatment and impairments in sexual functioning.

Finally, despite the significant associations between sexual functioning and a number of specific psychological measures, sexual functioning domains were not consistently associated with a global measure of quality of life. This finding lies in contrast to that of Milbury and colleagues [58] who found a significant association between global QOL and

sexual functioning in colorectal cancer survivors, although this finding was based on the FSFI Total score. In examining the lack of association between global QOL and sexual functioning, it is possible that the life-threatening and serious nature of rectal and anal cancer may place post-treatment symptomatology and dysfunction in a broader perspective for patients and, if applicable, their partners. This broadened perspective may be protective against the development of significant impairments in quality of life, despite the existence of long-term sexual impairments. Previous research has established that while quality of life and psychological well-being will often improve over time [e.g. 21], regardless of formal intervention, this is not necessarily the case in sexual functioning. The potential independence noted above may have clinical and empirical implications for female survivors. If indeed global QOL is not a reliable indicator of sexual functioning, specific assessment in clinical and research settings may be needed.

Limitations and Future Directions

The current study examined the characteristics of female rectal and anal cancer survivors who enrolled in an intervention targeting sexual dysfunction, which remains an understudied clinical issue within cancer care. Despite this strength, there are a number of limitations that must be noted in considering the reported findings. The sample surveyed was not intended to be representative of all female rectal or anal cancer survivors, as it was relatively homogeneous in terms of ethnic diversity, and all received care at a large urban cancer center. In addition, recruited individuals were at varying stages of post-treatment survivorship and were required to meet study eligibility.

In line with this limitation, no data was collected from age-matched controls, and thus no conclusions were drawn regarding the sexual functioning of study participants compared to the broader population. This is particularly important given that a substantial minority of women in this age group report a lack of sexual desire, with 12–14% reporting associated distress [59, 60]. This emphasizes the importance of assessing patients' pre-morbid sexual functioning when exploring the impact of treatment. Whereas the present study emphasized the relationship between psychological well-being and sexual functioning in sexually active women, it is not implied that women who are not sexually active could not benefit from an intervention focusing on sexual health. Finally, no information was collected regarding the sexual functioning of patients' partners' where appropriate. This has been identified as an important element of overall sexual life [61] and thus, once again, provides fertile ground for future research.

Summary

The number of individuals living beyond cancer treatment continues to grow, placing increasing emphasis on the long-term quality of life and well-being of survivors. Sexual functioning remains an important but often unaddressed domain of survivorship care, particularly in female survivors of rectal and anal cancer. A subgroup analysis established significant associations between sexual dysfunction and specific measures of psychological well-being in sexually active women, despite their overall quality of life being comparable to other survivor cohorts. Importantly, the association between Sexual/Relationship Satisfaction and measures of psychological well-being were consistent and strong, and therefore suggests that greater attention to this domain may be warranted in the development and implementation of interventions to assist this patient population.

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Table 1

Summary of Demographic and Treatment Information (n=70)

Demographics		Treatment Information	
Age		Time Since Treatment *	
Range	28–81	5 Years	74%
Mean	55.43	> 5 Years	24%
Race *		Mean (Median)	4.27 (4)
Caucasian	79%	Range	0.1–18 yrs
African American	9%	Cancer Type *	
Ethnicity *		Rectal Cancer	69%
Hispanic	7%	Anal Cancer	29%
Annual Income *		Pre Surgical Stage *	
Less than \$50,000	24%	1	31%
Marital Status		2	14%
Married	57%	3	41%
Divorced/Separated/Widowed	27%	Treatment *	
Single	16%	Neoadjuvant/Adjuvant	
Education *		Radiation Only	1%
Completed HS Only	7%	Chemo Only	11%
Completed College or Higher	57%	Radiation/Chemo	71%
Employment *		Surgery *	
Employed	47%	Surgical Treatment	73%
Retired	20%	Permanent Stoma	14%

Note: This table presents the highest percentage entries. A complete list of all categories is available from the authors. All percentages based on total sample.

* Data not available for all patients.

Table 2

Baseline Scores across Study Variables (n=70)

Scale	Mean (SD)	Range	Alpha*
FSFI Desire [^]	3.06 (0.99)	1.2–5.4	.76
FSFI Arousal [^]	3.53 (1.31)	1.2–6	.92
FSFI Lubrication [^]	3.62 (1.77)	1.2–6	.96
FSFI Orgasm [^]	4.02 (1.47)	1.2–6	.91
FSFI Sex/Rel Satisfaction [^]	3.99 (1.44)	1.2–6	.90
FSFI Pain [^]	3.44 (2.18)	0–6	.94
FSFI Total Score [^]	21.67 (6.52)	7.60–35.10	.93
Global QOL	76.30 (17.8)	25–100	.87
Emotional Functioning QOL	75.47 (21.5)	16.67–100	.85
BSI Depression	.59 (.69)	0–3	.87
BSI Anxiety	.65 (.60)	0–2.67	.77
IES-R Avoidance	7.33 (7.19)	0–29	.85
IES-R Hyperarousal	4.06 (4.99)	0–21	.82
IES-R Intrusion	8.54 (5.96)	0–22	.82
IES-R Total	19.93 (16.31)	0–68	.93
Body Image	69.24 (30.85)	0–100	.88

[^] FSFI data for sexually active women only (N=41)

* Chronbach's alpha

Intercorrelations (Pearson's r Correlation Coefficient) between Sexual Functioning and Psychological Outcomes for Sexually-active Participants ($n=41$)

Table 3

	FSFI Desire	FSFI Arousal	FSFI Lubrication	FSFI Orgasm	FSFI Sex/Rel Satisfaction	FSFI Pain	FSFI Total
IES-R		-.32*			-.49**		
Avoidance							
IES-R Intrusion	-.31*	-.40*		-.39*	-.49**		-.34*
IES-R		-.34*			-.46**		
Hyperarousal							
IES-R Total	-.33*	-.39*		-.32*	-.53**		-.32*
Global QOL		.31*			.48**		
Emotional QOL	.34*	.33*		.32*	.58**		.39*
BSI Depression		-.34*			-.50**		-.32*
BSI Anxiety	-.32*	-.43**		-.39*	-.45**		-.38*
Body Image	.46**	.53**	.37*	.38*	.70**		.56**

Note.

* $p < .05$, two-tailed.

** $p < .01$, two-tailed.