

Report
Couples Cancer Study: Pilot

Investigating the Impact on Couples of a Man's Localised Prostate or Colon Cancer Treatment

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Contents

Title page and investigators	1
Contents	2
Background, objectives, methods, results	3
Results continued	4
Conclusions	5
Table 1 Patient and partner participant demographic characteristics	6
Table 2 Factors influencing treatment choice for patients and partners	7
Table 3 EORTC-C30 results; comparison between prostate and colon cancer men	8
Table 3A EORTC-C30 results; comparison between patient and partner report	9
Table 3B EORTC-PR25; comparison between patients' and partners' scores	10
Table 3C EORTC-CR29; comparison between patients' and partners' scores	11
Table 4 Sexual Desire Inventory; comparison between patient and partner scores at baseline and follow-up	12
Table 5 Sexual function scales; IIEF – comparison between prostate and colon cancer men	13
Table 6 Sexual function scales; FSFI – comparison between prostate and colon cancer men's partners	14
Table 7 Correlation between men and their partners' sexual function scales - Baseline	15
Table 7A Correlation between men and their partners' sexual function scales – Follow-up	16
Table 8 Depression, Anxiety and Stress; comparison between patient groups and their partners	16
Table 9 Social Intimacy Scale; comparison between patient groups and their partners	17
Table 10 Dyadic Adjustment Scale-7; comparison between patient groups and their partners	18

Background

Prostate (PCa) and colon (CCa) cancers are two most commonly registered cancers in New Zealand, and are the second and third leading causes of death in men. Treatment options for PCa range from active surveillance, to surgery or radiotherapy (either brachytherapy or external beam radiotherapy), or some combination of these therapies. Similarly, for CCa options include surgery, radiotherapy, or chemotherapy and combinations of these therapies. However, patients with PCa may undergo androgen deprivation therapy (ADT) in addition to the other options. The two cancer types thus afford an opportunity for comparison of the relative impact on men of each of the therapy types in terms of surgery, radiotherapy or chemotherapy options, but more particularly in terms of the impact of hormone ablation. Additionally, treatment options for both cancer types have significant psychosocial impacts not only on the patients, but also on their partners.

The health-related quality of life (HRQoL) outcomes for these various treatment options have not been quantified in terms of the impact on a couple.

Objectives

This pilot study aimed to investigate the impact on health-related outcomes, sexual function and spousal experiences for both partners from diagnosis at baseline through various treatment options for the first three months. The pilot study findings will inform further longitudinal study to enable development of salient and effective interventions for couples faced with these issues.

Methods

The pilot study was a prospective three-month investigation planning to follow 20 recruited couples from baseline, through therapy. Participants completed questionnaires at each time-point. Questionnaires included the validated measures of quality of life in prostate cancer or colon cancer as appropriate, measures of stress, depression, anxiety, sexual function and intimacy. In addition interviews were conducted with some of the couples.

Results

Recruitment: Prospective recruitment at diagnosis via surgical and oncology services proved more difficult than anticipated. During the 1-year period in which the pilot was running, 12 couples were invited to participate. Baseline data was collected from 8 couples with follow-up questionnaires completed by 3 couples at time of reporting. Participant characteristics are summarised in **Table 1**.

Key findings from questionnaires are summarised in the tables included in this report. Because of the small numbers results are presented as medians and ranges for each scale without statistical significance testing since this process would generate potentially misleading results.

Factors influencing treatment choice: The items that the majority of men endorsed as very important factors influencing their choice of treatment were the chances of problems with bowel function and the recommendations from their doctor who was managing the cancer. Partners also endorsed the doctor's recommendations as very important; they were somewhat concerned about the need for escort to and from treatment when choosing treatment [**Table 2**].

HRQoL: Patient comparison: Overall on this measure men with colon cancer seem to fare worse than men with prostate cancer. They had had lower median global health status and function scores across range except for emotional function at baseline. At follow-up colon

cancer men had a lower median global health score, physical function score and social function score than prostate cancer men [Table 3].

HRQoL: Couples comparison: The patient/partner comparisons showed that at baseline partners regarded their men as having lower overall quality of life than the men reported themselves. The partners also reported lower role function, cognitive function and social function in their men than the patients reported at baseline. The patients reported lower levels of emotional functioning pre-treatment but their partners thought they were functioning less well after treatment. The patients regarded their physical function as having worsened following treatment. Partners reported the men's emotional function and cognitive function was lower following treatment than the patients reported [Table 3A].

The couples with prostate cancer reported more urinary bother at follow-up than baseline, some issues with bowel symptoms, and decreases in sexual activity levels and functioning [Table 3B].

Colon cancer couples reported fewer changes during the study on the HRQoL measures, but the numbers in this group were small so results must be treated with caution [Table 3C].

Sexual desire and function scales: Sexual desire levels in the patients were higher at baseline than their partners, but the situation was reversed at the time the follow-up measures were completed, with the patients recorded scores half that of their baseline levels [Table 4].

Men with prostate cancer had better sexual function totals at baseline and improvements in follow-up IIEF scores, than men with colon cancer, whose scores remained same at each measure point. However it should be noted that the numbers in the pilot were small and the follow-up period was short; it is often the case that men find sexual activity more difficult later in their recovery from prostate cancer therapies. This is the rationale for the study as originally planned, being carried out over several years [Table 5].

Partners of the men with cancer reported much worse sexual function totals at follow-up than baseline, indicating less sexual activity, or less satisfaction with that activity; this despite the men scoring at similar levels [Table 6].

Correlations between patients' and partners' sexual function scores were carried out at baseline and follow-up [Tables 7, 7A]. Results showed men's overall satisfaction significantly correlated with partners' sexual function at follow-up, whereas it was not at baseline. Again, these findings must be interpreted with caution since the numbers involved are very small.

Psychological impacts – depression, anxiety and stress: While most participants did not experience depression, anxiety or undue stress according to the measures used, anxiety and depression at clinical levels were recorded in three cases at baseline in the men, and also in partners. Anxiety remained significant for one woman at follow-up [Table 8].

Social intimacy and dyadic adjustment: These two measures were used to quantify significant changes in a couple's relationship during the study time-frame. Patients' baseline scores ranged lower than their partners, but at follow-up partners' scores ranged lower than patients' scores. Within-subject comparisons showed one man recorded a rise in social intimacy, two recorded slight drops, and one man did not change.

All of the partners recorded decreases in social intimacy over the study time-frame [Table 9]. The decreases in social intimacy were substantially larger for the women whose partners had colon cancer, with a 45 point (28%) drop in one and a 47 point (36%) drop for the other compared to 10 (6%) and 13 point (8%) drops for the prostate cancer men's partners.

The Dyadic Adjustment Scale-7 is a short version of the commonly used measure used to differentiate between distressed and adjusted marriages. At baseline there was little difference between men and their partners regarding dyadic consensus although the women's

scores ranged lower than the men's. Dyadic cohesion rose a little for the couples at follow-up, as did satisfaction. Overall scores rose for patients and their partners at follow-up; patients (29%), and partners (11%) [Table 10].

Conclusions

Conducting this pilot study has been valuable in understanding the need for enrolment processes to be simple to apply in the clinical context; this is apparently problematic in the WDHB clinical environment. Suggestions as to better management of this stage included a dedicated recruitment person – not something the study had funding for. However the questionnaire findings demonstrate the viability of the methods proposed once recruitment has been achieved. The interview data was overviewed for this report and it was concluded that with few participants, the risk to their privacy was too great to make quotations from the transcripts. However participants spoke highly of their clinicians, and the treatment they received. Most were not distressed by the changes the cancer diagnosis had wrought in their lives, having adopted coping mechanisms to manage the unfolding disease and treatment progression. However, there were only a small number of participants in this pilot, so we cannot conclude that these people represent the overall experiences of couples with these conditions.

Table 1. Patient and partner participant demographic characteristics.

Characteristic	Patients (n)	All Patients (n)	PCa men	CCa men	Partners (n)
Invited	12	8	3	12	
Recruited	8	6	2	7	
3 month follow-up	4	2	2	4	
<i>Details below pertain to participants only</i>					
Age (yrs)					
Median	62.5	66	53	58	
Range	43-81	55-81	43-63	42-67	
Ethnicity					
NZ European	7	6	1	6	
Maori	1	-	1	1	
Relationship status					
Married	6	4	2	5	
De facto	2	2	-	2	
Years with partner					
Mean	31	21.9	32	29.3	
Range	2-43	2-43	25-39	2-42	
Partner's menstrual status					
Still menstruating regularly	-	-	-	-	2
Post-menopausal	-	-	-	-	3
Other (eg. Hysterectomy)	-	-	-	-	2
Number of medications listed					
Mean	5.2	3.8	4	2	
Range	0-9	0-9	0-8	0-4	

Table 2. Factors influencing treatment choice for patients and partners

Item	Patient endorsed (n=8)			Partner endorsed (n=7)		
	Not important	Somewhat important	Very important	Not important	Somewhat important	Very important
Amount of time required to complete treatment	6	0	2	3	3	1
Amount of time required to recover from treatment	4	2	2	4	2	1
Impact on usual daily activities	3	4	1	3	3	1
Need for escort to/tfrom treatment	6	1	1	3	4	0
Inconvenience and burden on patient's family during treatment and recovery	4	3	1	6	1	0
The amount of out-of-pocket costs that patient expects will not be covered by any type of insurance	4	3	0	5	2	0
Chances of problems with urinary function	3	2	3	3	2	2
Chances of problems with bowel function	3	1	4	3	2	2
Chances of problems with sexual function	3	2	3	3	1	2
Chances of pain caused by treatment	3	2	3	3	2	2
Chances of tiredness or fatigue following treatment	4	3	1	4	3	0
Chances of depression/anxiety	6	1	1	5	1	1
Recommendations from patient's doctor(s) who are managing the cancer	0	1	7	0	3	4
Wife or partner preference for a particular treatment	3	3	2	2	3	2
Close family member preference for a particular treatment	4	2	2	5	2	0
Recommendations from someone the patient knows who was treated for prostate cancer	4	3	1	2	3	1

Note. Shaded responses indicate >50% of sample endorsed that response.

The items that the majority of men endorsed as very important factors influencing their choice of treatment were the chances of problems with bowel function and the recommendations from their doctor who was managing the cancer. Partners also endorsed the doctor's recommendations as very important; they were somewhat concerned about the need for escort to and from treatment when choosing treatment.

Table 3. EORTC-C30 results; comparison between prostate and colon cancer men

Scale	Baseline			Follow-up				
	Prostate Patients n = 6		Colon Patients n = 2		Prostate Patients n = 2		Colon Patients n = 2	
	Median	Range	Median	Range	Median	Range	Median	Range
Global health status	87.53	33-100	79.2	75-83	95.8	92-100	70.8	67-75
Functional scales								
Physical function	96.7	67-100	83.3	80-87	93.3	87-100	86.7	73-100
Role function	100	100	83.3	67-100	100	100	100	100
Emotional function	87.5	8-100	91.7	83-100	95.8	92-100	100	100
Cognitive function	100	83-100	75.0	67-83	100	83-100	100	100
Social function	100	83-100	75.0	67-83	100	100	91.7	83-100
Symptom scales/items								
Fatigue	11.1	0-56	27.8	22-33	0	0	16.7	0-33
Nausea & vomiting	0	0-17	8.3	0-17	0	0	0	0
Pain	0	0-17	0	0	8.3	0-17	0	0
Dyspnoea	0	0-33	33.3	33	16.7	0-33	0	0
Insomnia	0	0	16.7	0-33	0	0	0	0
Appetite loss	0	0-33	33.3	33	0	0	16.7	0-33
Constipation	33.3	0-67	16.7	0-33	16.7	0-33	0	0
Diarrhoea	0	0-67	16.7	0-33	0	0	16.7	0-33
Financial difficulties	0	0-33	0	0	0	0	0	0

CCa men had lower median **global health** status and **function scores** across range except for **emotional function** at baseline.

At follow-up CCa men had lower median **global health score**, **physical function score** and **social function score** than PCa men.

Overall on this measure men with colon cancer seem to fare worse than men with prostate cancer.

Table 3A. EORTC-C30 results; comparison between patient and partner report.

Scale	Baseline			Follow-up		
	Patient n = 8	Partner n = 4	Patient n = 4	Partner n = 3	Median	Range
Global health status	83.3	0-67	66.7	0-58	83.3	66.7-100
Functional scales						
Physical function	93.3	67-100	93.3	67-100	93.3	73-100
Role function	100	67-100	83.3	33-100	100	100
Emotional function	87.5	8-100	91.7	25-100	100	92-100
Cognitive function	91.7	67-100	83.3	50-100	100	86-100
Social function	100	67-100	83.3	50-100	100	83-100
Symptom scales/items						
Fatigue	11.1	0-56	22.2	0-55	0	0-33
Nausea & vomiting	0	0-17	0	0-17	0	0
Pain	0	0-17	0	0-17	0	0-17
Dyspnoea	16.7	0-33	0	0-33	0	0-33
Insomnia	0	0-33	0	0-33	0	0-33
Appetite loss	0	0-33	33.3	0-33	0	0-33
Constipation	33.3	0-67	33.3	0-33	0	0-33
Diarrhoea	0	0-67	0	0-33	0	0-33
Financial difficulties	0	0-33	0	0	0	0

EORTC-C30 measures quality of life under several sub-scale headings including several functional and a number of symptom scores.

Global health status of patient reported to be lower by partners pre-op than patients. At follow-up no difference between groups.

Reported patient **Physical function** same at baseline and lower by patients than partners at follow-up.

Reported patient **Role function** lower by partners than patient pre-op. At follow-up no difference

Reported patient **Emotional function** lower from patients than partners pre-op; lower by partners than patients at follow-up.

Reported **Cognitive function** of patients said to be lower by partners than patients at baseline; and again at follow-up.

Social function reported lower by partners than patients at baseline; median same at follow-up.

Table 3B. EORTC-PR25; comparison between patients' and partners' scores

Symptom Scale	Baseline			Follow-up			Follow-up		
	Prostate Patients n = 6		Partners n = 4	Median	Range	Median	Range	Median	Range
Urinary	14	0 - 15	12	8 - 12	18	14 - 22	15	13 - 17	
Continence Aid	-	-	-	-	-	-	-	-	-
Bowel	4	4 - 5	4	3 - 5	5.5	4 - 7	5.5	4 - 7	
Hormone Treatment Related	7.5	6 - 11	6	6 - 8	7	7	7	6 - 8	
Sexually Active	5	3 - 7	6	4 - 6	3.5	2 - 5	4	2 - 6	
Sexual Function - male	7	0 - 12	9.5	9 - 10	5	0 - 10	5	0 - 10	
Sexual function - female			5	2 - 5			1.5	0 - 3	
Total	36	29 - 48	41.5	39 - 43	39	38 - 40	38	32 - 44	

Men and their partners both rated urinary bother higher at follow-up than baseline.

Bowel issues remained similar across the study and were rated similarly by both partner and patient.

Hormone treatment related scoring also remained similar across study, and was rated similarly by men and their partners.

Partners scored sexual activity slightly higher than the patients at each measurement; activity scores dropped slightly at follow-up.

Sexual function was rated more highly by partners than patients at baseline, but similarly by both at follow-up.

Partners rated their sexual activity enjoyment much lower at follow-up.
Overall scores remained fairly constant across the time studied.

Table 3C. EORTC-CR29; comparison between patients' and partners' scores

Symptom Scale	Baseline			Follow-up			Follow-up	
	Colon Ca Patients n = 2	Median	Range	Partners n = 2	Median	Range	Colon Ca Patients n = 2	Partners n = 2
Urinary frequency	4.5	4 - 5	3	2 - 4	3	3	4.5	3 - 6
Body image	2.5	2 - 3	4	3 - 5	3	3	3.5	3 - 4
Sexual Interest - male	1	0 - 2			1.5	0 - 3		
Sexual Interest - female			2.5	0 - 5			1.5	0 - 3
Individual items	22	19 - 25	26.5	23 - 30	18.5	12 - 25	20	15 - 25
Total	32.5	28 - 37	37.5	30 - 45	28	20 - 36	30.5	25 - 36

Total HRQoL scores dropped across study time-frames, but few separate scales were notably different.
 Sexual interest on this measure rose in patients and dropped in partners at follow-up.

Table 4. Sexual Desire Inventory; comparison between patient and partner scores at baseline and follow-up

Scale	Baseline			Follow-up		
	Patient n = 8	Partner n = 7	Patient n = 4	Partner n = 4	Median	Range
Dyadic [max=62]	37	12-47	36	14-54	18.5	6-41
Solitary [max=23]	2.5	0-19	1	0-17	0	0-4
Total [max=109]	48.5	24-82	37	14-90	21.5	9-57
					40.5	22-51

The Sexual Desire Inventory records a person's interest in engaging in sexual activity.

At baseline patient and partner dyadic desire very similar, but at follow-up patient desire has halved while partner desire has remained similar to baseline.

Solitary sexual desire (usually for masturbation) higher in patients at baseline than follow-up, and lower in both patient and partners at follow-up.

Total sexual desire scores higher in patients than partners at baseline, but halved in patients at follow-up and higher in partners at follow-up.

Table 5. Sexual function scales; IIEF – comparison between prostate and colon cancer men

Scale	Baseline			Follow-up		
	Prostate Patients n = 6		Colon Patients n = 2		Colon Patients n = 2	
	Median	Range	Median	Range	Median	Range
Erectile function [max 30]	13.5	1-29	12.5	6-19	21	13-29
Orgasmic function [max 10]	6	0-10	2	0-4	9.5	9-10
Sexual Desire [max 10]	6.5	4-9	6.5	5-8	8	7-9
Intercourse satisfaction [max 15]	8.5	0-12	6.5	0-13	10	9-11
Overall satisfaction [max 10]	7	2-10	6	4-8	9	8-10
IIEF total [max 75]	45	10-65	33.5	15-52	57.5	50-65
					33.5	15-52

The International Index of Erectile Function records aspects of a man's sexual activity with a focus on his erectile capability. While numbers are small, prostate men had better IIEF totals at baseline and improvements in follow-up IIEF scores than colon men (whose scores remained same at each measure point). However it should be noted that the follow-up period was short; it is often the case that men find sexual activity more difficult later in their recovery from prostate cancer therapies. This is the rationale for the study as originally planned, being carried out over several years.

Table 6. Sexual function scales; FSFI – comparison between prostate and colon cancer men's partners

Scale	Prostate Partners Baseline n = 6			Colon Partners Baseline n = 2			Prostate Partners Follow-up n = 2			Colon Partners Follow-up n = 2		
	Median	Range	Median	Range	Median	Range	Median	Range	Median	Range	Median	Range
Sexual desire [max 6]	2.4	1.8-3.6	3.3	3-3.6	1.8	0-3.6	3	2.4-3.6				
Arousal [max 6]	4.2	0-6	5.1	4.2-6	2.7	0-5.4	2.3	0-4.5				
Lubrication [max 6]	3.3	0-6	5.7	5.4-6	1.8	0-3.6	2.9	0-5.7				
Orgasm [max 6]	5.6	0-6	5	4-6	3	0-6	2.4	0-4.8				
Satisfaction [max 6]	4	1.2-6	5.2	4.4-6	5.4	4.8-6	2.6	0-5.2				
Pain [max 6]	4.4	0-6	0	0	0.6	0-1.2	1.6	0-3.2				
FSFI total [max 36]	25.4	3.6-32.1	24.3	21-27.6	15.3	4.8-25.8	14.7	2.4-27				

The Female Sexual Function Scale details aspects of a woman's sexual activity under several headings.

At baseline partners had FSFI total scores just below clinically functional cut-off (25.7) but at follow-up totals were 10 points less for each group, indicating less sexual activity, or less satisfaction with that activity.

Table 7. Correlation between men and their partners' sexual function scales – Baseline (n=7)

SCALE	IIEF	Erectile function	Orgasmic function	Sexual Desire	Intercourse satisfaction	Overall satisfaction	IIEF total
FSFI							
Sexual Desire	0.432	0.644	0.464	0.692	0.498	0.622	
Arousal	0.802, p = .03	0.890, p = .01	0.644	0.826, p = .02	0.421	0.896, p = .01	
Lubrication	0.798, p = .03	0.847, p = .02	0.693	0.826, p = .02	0.309	0.877, p = .01	
Orgasm	0.748	0.803, p = .03	0.579	0.761, p = .05	0.448	0.831, p = .02	
Satisfaction	0.556	0.649	0.764, p=.05	0.624	0.608	0.702	
Pain	0.650	0.431	-0.292	0.272	-0.262	0.425	
FSFI total	0.835, p = .02	0.846, p = .02	0.509	0.772, p = .04	0.327	0.867, p = .01	

Note. Shaded correlations are statistically significant.

Table 7A. Correlation between men and their partners' sexual function scales – Follow-up (n=4)

SCALE	IIEF	Erectile function	Orgasmic function	Sexual Desire	Intercourse satisfaction	Overall satisfaction	IIEF total
FSFI							
Sexual Desire	0.741	0.700	0.817	0.815	0.554	0.757	
Arousal	0.873	0.782	0.992, p=.01	0.928, p=.02	0.925	0.922	
Lubrication	0.997, p = .01	0.972, p = .03	0.953, p = .05	0.970, p = 0.3	0.889	0.998, p = .01	
Orgasm	0.859	0.764	0.988, p = .012	0.977, p = .02	0.922	0.911	
Satisfaction	0.608	0.520	0.681	0.672	0.895	0.663	
Pain	0.981, p = .02	0.999, p = .0001	0.841	0.873	0.785	0.952, p = .05	
FSFI total	0.941	0.872	0.997, p = .01	0.997, p = .01	0.957, p = .04	0.974, p = .03	

Table 8. Depression, Anxiety and Stress; comparison between patient groups and their partners

Scale	Baseline			Follow-up		
	Patient n = 8	Partner n = 7	Patient n = 4	Partner n = 3	Patient n = 4	Partner n = 3
Depression [11+ = case]	Median 1	Range 0 - 11	Median 3	Range 1 - 13	Median 0.5	Range 0 - 1
Anxiety [11+ = case]	2.5	0 - 15	9	0 - 15	0	0 - 1
Stress [15+ = mild]	1.5	0 - 12	9	1 - 13	0	0 - 3
					Median 4	Range 2 - 7
					4	1 - 11
					5	0 - 8

The measure used for these psychological characteristics was a combination of the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and the Stress sub-scale from another measure (the Depression Anxiety and Stress Scale, Lovibond & Lovibond, 1986). The HADS was used because it is frequently employed in medical settings, but the stress scale was added as the HADS does not take account of stressors separately.

While the median scores were all in the normal range for these scales, two men recorded clinical anxiety, and one depression at baseline. Stress levels, while higher in some men than others, were all less than clinically relevant at baseline. These all returned to normal levels by follow-up. The men's partners recorded slightly higher median scores for anxiety and depression, with three cases of anxiety and two of depression at baseline, with stress just below clinical significance for one woman. At follow-up anxiety remained for one woman, but the remainder were less affected than at baseline. These scores indicate that the couples felt relevant psychological impact of the cancer diagnosis.

Table 9. Social Intimacy Scale; comparison between patient groups and their partners

Scale	Development Sample Married Males n = 15	Development Sample Married Females n = 15	Baseline Patient n = 8	Baseline Partner n = 7	Follow-up Patient n = 4	Follow-up Partner n = 4
Median	124	140	143.5	144	145.5	131.5
Range	66-161	95-157	108-169	128-169	118-151	85-159

The Social Intimacy Scale describes the levels of closeness with significant others (in this study, one's partner).

At baseline all participants had higher social intimacy scores than the developmental sample (average age of that sample was 36 years).

Patients' baseline scores ranged lower than their partners, but at follow-up partners' scores ranged lower than patients' scores.

Within-subject comparisons showed one man recorded a rise in social intimacy, two recorded slight drops, and one man did not change.

All of the partners recorded decreases in social intimacy over the study time-frame. The decreases in social intimacy were substantially larger for the women whose partners had colon cancer, with a 45 point (28%) drop in one and a 47 point (36%) drop for the other compared to 10 (6%) and 13 point (8%) drops for the prostate cancer men's partners.

Table 10. Dyadic Adjustment Scale-7; comparison between patient groups and their partners

Scale	Baseline			Follow-up		
	Patient n = 8	Partner n = 7	Patient n = 4	Partner n = 4	Patient n = 4	Partner n = 4
Dyadic consensus [max 15]	12	9 - 15	Median	Range	Median	Range
Dyadic cohesion [max 15]	8	7 - 12	10	3 - 14	11.5	0 - 13
Global dyadic satisfaction [max 6]	4	3 - 5	5	3 - 5	10.5	3 - 14
Total score DAS-7 [max 36]	21	21 - 30	27	16 - 30	27	9 - 31
					30	18 - 32

The Dyadic Adjustment Scale-7 is a short version of the commonly used measure developed to report on the characteristics of a couple's marital relationship. This scale is used to differentiate between distressed and adjusted marriages. At baseline there was little difference between men and their partners regarding dyadic consensus although the women's scores ranged lower than the men's. Dyadic cohesion rose a little for the couples at follow-up, as did satisfaction. Overall scores rose for patients and their partners at follow-up; patients (29%), and partners (11%). However one man recorded a much lower score at follow-up, but taken in conjunction with the follow-up score of his partner and the couple's high scores on the intimacy scale, it appears the man misread the instructions and recorded scores under an incorrect response.