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**Title: Osteoarthritis: Patient expectations about future pain, stiffness and function**

**Short Title: Osteoarthritis: Patient expectations**

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## **Abstract**

**Objectives.** To examine the difference between osteoarthritis patients' self-reported assessments of current pain, stiffness and physical function and their expectations of these symptoms in 1 and 5 years' time. To determine the significant predictors of positive expectations.

**Method.** 80 patients completed ratings of baseline assessments and 1 and 5 year expectations of pain, stiffness and physical function using the Western Ontario and McMaster Osteoarthritis Index (WOMAC). Measures of illness perceptions, coping styles, health values, satisfaction, quality of life, optimism, self-esteem and moods were also collected at baseline. Agreement between patient current assessment and expectations were calculated using intra class correlations. Paired-sample t-tests were conducted to look at differences between assessments. Univariate logistic regressions were then performed to identify the variables significantly associated with positive expectations of pain, stiffness and function. Significant variables ( $p < 0.05$ ) were entered into a forward stepwise multivariate logistic regression to identify unique independent predictors of positive expectations for each of the WOMAC subscales.

**Results.** Differences were found between current assessments and expectations with the majority of patients being positive about future symptoms. There were some differences between the predictors for 1 and 5-year expectations with current assessments of health status only affecting 5-year expectations.

**Conclusion.** It is necessary to investigate further the variables that may contribute to positive expectations in OA patients in order to more effectively manage the condition.

**Key words.** Osteoarthritis, patient expectations, quality of life, pain, function

## Introduction

There is evidence to suggest, across a wide range of conditions, that the expectations that patients have about their health, disease course and treatment may influence clinical outcomes. A number of systematic reviews have now been conducted that support this association, including positive recovery expectations linked to better health outcomes across a range of conditions (Mondloch, Cole, & Frank, 2001), a strong predictive role of recovery expectations in people with acute non-specific lower back pain (Iles, Davidson, Taylor, & O'Halloran, 2009) and a small significant effect of outcome expectations on outcomes in psychotherapy (Constantino, Arnkoff, Glass, Ametrano, & Smith, 2011). However, less is known about the role of patient expectations in long-term conditions such as osteoarthritis (OA).

OA is a highly prevalent disease, with evidence of either clinical or radiographic OA in at least 85% of the population by the age of 75 years (Lawrence, Bremner, & Bier, 1966). OA is characterised by pain, stiffness, functional difficulties and in some cases joint deformity. Knee and hip joint replacement surgery can provide substantial benefit in cases of unrelenting pain or when joint function is severely compromised (Sack, 1995). Nonetheless it remains an incurable chronic condition. The role of patient expectations is of particular interest in OA as diagnosis and treatment are dependent in part on self-reported symptoms such as pain and because the disease can result in periodic flares.

A review of total hip (THA) and total knee arthroplasty (TKA) concluded that there was no consistency in the association between patients' pre-operative expectations and treatment outcomes for THA and TKA (Haanstra et al., 2012). However a recent study by Foster et al (2012) (Foster, Thomas, Hill, & Hay, 2010) found that when a patient with knee osteoarthritis expects their treatment to be highly successful they are almost twice as likely to be classified as a treatment responder according to clinical criteria. Suarez-Almazor et al (Suarez-Almazor, Conner-Spady, Kendall, Russell, & Skeith, 2001) maintain that patients' expectations in relation to musculoskeletal diseases are an important determinant of the meaning they assign to their

health and could therefore influence patients' subjective assessment of their health status. Such expectations may be based on a number of factors; such as personal experience with surgery or information gathered through discussions with health care providers (Gandhi, Davey, & Mahomed, 2009), coping strategies, or illness perceptions.

Despite this body of literature little is known about the determinants of patient expectations or how these expectations affect self-reported health assessments in patients with OA. The primary objective of the present study was to examine the difference between OA patients' current assessments of pain, stiffness and physical function and their future expectations of these symptoms in 1 and 5 years' time. The secondary objective of this study was to identify the factors that predict positive expectations about the future.

## **Method**

### ***Ethics***

Ethical approval was obtained from a local Research Ethics Committee (REC).

### ***Subjects***

Patients were eligible for recruitment if they were clinically diagnosed with hip or knee OA by a Consultant, were aged 18 years or over and were able to read and understand English.

### ***Procedure***

Over the course of a two year period, a consecutive convenience sample of patients with diagnosed OA was recruited during routine outpatient visits at a London Hospital. Those agreeing to participate provided informed written consent and were asked to complete a series of self-report questionnaires.

### ***Study instruments***

#### **Demographics**

Data were collected on age, gender, employment and marital status, recommended, tried and expected treatments, time since diagnosis and co- morbidities.

### **Function**

- a) Three individual visual analogue scales (VAS) were used to assess pain, stiffness and fatigue “because of the patients’ arthritis in the past week”, anchored at the ends with the descriptors 0 = no and 100 = very severe.
- b) The Modified HAQ (MHAQ) (Pincus, Summey, Soraci, Wallston, & Hummon, 1983) is a valid and reliable measure of functional disability. Final scores ranged from 0-3, with 0 indicating perfect function and 3 severe disability.
- c) The WOMAC is a valid and reliable multidimensional measure of pain, stiffness and physical function (Bellamy, 2005; Bellamy, 1993) in the previous 48 hours. Each subscale score was obtained by adding together response values for each component item (pain 0-20, stiffness 0-8, and physical function 0-68), with higher scores indicating worse health.

### **Quality of life**

The Medical Outcomes Study 36-Item Short Form (SF-36™) (Ware, Kosinski, & Keller, 1994) assesses 8 QoL domains: physical function, role limitation in physical function, bodily pain, general health, vitality, social function, role limitation in emotional problems and mental health in the past 4 weeks. Two summary scores, the physical component summary (PCS) and mental component summary (MCS) scores were also calculated. Scores ranged from 0 (extreme symptoms or poor health) to 100 (no symptoms or best possible health).

### **Health Value**

The 4-item Health Value (HV); (Lau, Hartman, & Ware, 1986) scale was used to assess the value participants place on their health. Scores ranged from 4 to 28 with higher scores indicating that a high value was placed on health. The authors report good reliability.

### **Satisfaction**

Patient satisfaction with medical treatment was measured with the Client Satisfaction Questionnaire (CSQ-8) (Attkisson & Zwick, 1982), a valid and reliable generic measure that is used to assess patient satisfaction in any clinical setting. Higher scores indicated a greater degree of satisfaction.

### **Illness Representations**

Patients' illness representations were measured using 4 subscales (identity, timeline, consequence, and cure/control) from the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996). *Identity* measures the extent to which the patient experiences a number of symptoms as part of their OA from "all of the time" to "never". Scores range from 0 to 12, with higher scores indicating more symptoms perceived to be associated with OA. *Timeline* measures perceptions about the likely duration of the illness. *The consequences subscale* measures patients' beliefs about personal consequences and outcomes of OA and *the cure/control subscale* measures beliefs about the extent to which OA can be cured or controlled. For these final 3 scales higher scores indicate longer disease duration, greater personal impact and an increased sense of control. The IPQ has proven validity and reliability across a range of illnesses including RA (Scharloo et al., 1998).

### **Coping**

The Brief COPE (Carver, 1997) is a valid and reliable 28-item scale, used to assess 14 conceptually different coping strategies: active coping, planning, positive reframing, acceptance, humour, religion, use of emotional support, use of instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement and self-blame. Each strategy is captured by two items, and responses are made on 4-point Likert-type scale from 1 ("I don't do this at all") to 4 ("I do this a lot"); With higher scores representing greater engagement in that particular coping strategy.



### **Optimism**

Optimism was assessed by an abbreviated 4-item version of (Scheier & Carver, 1985) Life Orientation Test (LOT). High total summed scores indicate more optimism.

### **Mood**

The 14-item Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) is a valid and reliable self-screening questionnaire for depression and anxiety in patients with physical health problems. Total scores ranged from 0 to 21; scores of less than 7 indicate no depression/anxiety; 8 to 10 moderate anxiety and depression and greater than 11 'caseness', a high likelihood that a person would be diagnosed to be suffering from clinical anxiety or clinical depression.

### **Self-esteem**

Global self-esteem was measured by the Rosenberg Self-Esteem Scale (RSE) (Rosenberg, 1965). Scores for each of the 10 items range from 0 to 3 with higher scores indicating more self-esteem. This scale is one of the most widely used measures and the author reports good reliability and validity.

### **Expectations in 1 and 5 years**

- a) Patients' expectations of fatigue were assessed by two VAS (Wolfe, Hawley, & Wilson, 1996), anchored at the ends with the descriptors "0 = no fatigue" and "100 = very severe fatigue".
- b) Patient expectations of pain stiffness and physical function were assessed using reworded items from the WOMAC to include prospective timeframes of 1 and 5 years instead of the previous 48 hours.

### **Data analysis**

All data were analysed using SPSS 14.0. Mean value imputation was used on all scales assuming 50% of the items were completed. For the SF-36™ if one or more of the 8 subscales were missing then the PCS and MCS

were not calculated (Ware et al., 1994). Cronbach's alpha coefficients were calculated for each dataset to assess the internal reliability of the scales used, scores ranged from 0.40 to 0.99. Alphas for HV scale, Brief COPE behavioural disengagement subscale and IPQ cure/control were less than 0.70, therefore any analysis using these variables should be interpreted with caution.

Levels of agreement between patient current assessment and expectations on each of the WOMAC subscales were calculated using intra class correlations (ICC). A series of paired-sample t-tests were conducted to look at differences between the participant's current assessment of symptoms and their 1 and 5-year expectations.

To examine the direction and magnitude of the difference between current assessment and expectations, patient's expectation scores (for 1 and 5 years) were subtracted from current assessment on all 3 subscales of the WOMAC. An expectation score of '0' indicates no difference between current assessment and expectations; a negative value indicates an expectation of worse symptoms in 1 and 5 years time and a positive value an expectation of less pain, stiffness and restricted function than at present. To examine predictors of positive expectations these groups were treated as a binary dependent variable with those expecting no change in the future recoded as missing and excluded from the logistic regression analyses. Predictors of positive expectations in relation to pain, stiffness and function compared to current assessments were then explored.

Only significantly variables ( $p < 0.05$ ) within a univariate logistic regression were entered into a multivariate logistic regression to identify the unique independent predictors of positive expectations. A stepwise approach was used as this was an exploratory study.

## Results

### Study population

Informed consent was gained from all study participants.

Demographic questionnaires were completed by 80 patients with a mean age of 64.39 years (SD=10.93; range 31-87); 45 of whom were female. 62 patients expected to have surgery in the future with 5 of those also expecting to undergo some other treatment also. Only 14 patients did not expect to receive any treatment in the future.

### Expectations

#### *Overall patient expectation*

Figures 1 and 2 illustrate that more participants had positive expectations about their future levels of pain, stiffness and function than those expressing the same or negative expectations. A series of paired t-tests (Table 1) found statistically significant differences in mean scores for pain, stiffness and function when comparing current assessment to 1 and 5-year expectations. With more pain and stiffness and less function expected at 1 year when compared to 5 years. The magnitude of the differences in the means was large (eta squared ranged 0.18 – 0.31).

#### *What predicts positive and negative patient expectations?*

Results for the univariate logistic regression can be found in Table 2. Only significant variables were entered into the multivariate analysis, the final models for which can be found in Table 3.

#### One- year expectations

- **Pain**

Optimism, self-esteem and perceptions of cure/control were entered into the multivariate logistic regression. The overall model was statistically significant,  $X^2(1, n=58) = 5.908, p < 0.05$ , indicating that the model was able to distinguish between patients who had positive and negative expectations. Nagelkerke's

R<sup>2</sup> explained 13.6% of the variance in expectations. Correct classification of cases moved from 69% to 74.1% in the final model, with 90% of participants with positive expectations and 38.9% of participants with negative expectations correctly classified. Only optimism made a unique statistically significant contribution to the model, with an odds ratio of 1.19. Beta values indicate that those participants who expect their pain in 1-year's time to be better than at present report greater levels of optimism.

- **Stiffness**

Only behavioural disengagement as measured by COPE was significant in the univariate analyses. The final model was statistically significant,  $\chi^2 (1, n=43) = 5.813, p < 0.05$ . Nagelkerke's R<sup>2</sup> explained 18.2% of the variance in 1-year positive patient expectations. Correct classification of cases moved from 72.1% to 74.4% in the final model, with 90.3% of participants with positive expectations and 33.3% of participants with negative expectations correctly classified. The odds ratio for behavioural disengagement was 0.24. Beta values indicate that those participants who rate their stiffness in 1 year's time to be better than at present report lower levels of behavioural disengagement.

- **Function**

Only perceived cure/control in the univariate analyses was significantly related to positive 1-year expectations of function. The final model was statistically significant,  $\chi^2 (1, n=60) = 7.111, p < 0.01$ . Nagelkerke's R<sup>2</sup> explained 16% of the variance in expectations. Correct classification of cases moved from 71.7% to 75% in the final model, with 90.3% of participants with positive expectations and 33.3% of participants with negative expectations correctly classified. The odds ratio for the control score was 5.69. Beta values indicating that those participants who expect their function in 1 year's time to be better than at present report greater levels of perceived controllability.

### Five-year expectations

- **Pain**

Expected surgery, self-distraction, perceptions of cure/control and timeline, SF-36 social functioning and bodily pain and current WOMAC pain were entered into the multivariate analysis. The overall model was statistically significant,  $\chi^2 (1, n=65) = 28.480, p < 0.05$ . Nagelkerke's  $R^2 = 0.519$  indicated the predictor variables were associated with the outcome variable. Correct classification of cases moved from 73.8% to 87.7% in the final model, with 95.8% of participants with positive expectations and 64.7% of participants with negative expectations correctly classified after the third step. After the final step expected future surgery, perceptions of cure/control and pain made statistically significant contributions to the model, with odds ratios of 14.18, 9.24 and 0.88 respectively. Beta values indicate that those participants who expect their pain in 5-year's time to be better than at present report expectations of surgery, greater levels of bodily pain and perceived controllability.

- **Stiffness**

Employment status, relatives' health, expected surgery, health values and perceptions of cure/control and timeline were entered into the multivariate analysis. The overall model was statistically significant,  $\chi^2 (1, n=49) = 18.779, p < .05$ . Nagelkerke's  $R^2 = .474$  indicated the predictor variables were associated reasonably well with the outcome variable. Correct classification of cases moved from 75.5% to 85.7% in the final model, with 91.9% of participants with positive expectations and 66.7% of participants with negative expectations correctly classified after the second step. After the final step expected future surgery and health value made statistically significant contributions to the model, with odds ratios of 28.54 and 1.24 respectively. Beta values indicate that those participants who expect their stiffness in 5 year's time to be better than at present report greater levels of health value and expect surgery at some point in the future.

- **Function**

In the univariate analyses, 15 predictor variables were significantly related to 5-year expectations of function and were entered into the multivariate model. The overall model was statistically significant,  $\chi^2 (1, n=69) = 34.31, p < 0.05$ , indicating that it was able to distinguish between patients who had positive and negative expectations. Nagelkerke's  $R^2 = 0.55$  indicated the predictor variables were associated with the outcome variable. Correct classification of cases moved from 68.1% to 82.6% in the final model, with 91.5% of participants with positive expectations and 63.6% of participants with negative expectations correctly classified after the third step. After the final step only expected future surgery, perceptions of cure/control and pain made statistically significant contributions to the model, with odds ratios of 25.70, 7.22 and 0.91 respectively. Beta values indicating that those participants who expect their function in 5 year's time to be better than at present report, expectations of future surgery, greater levels pain and perceived controllability.

## **Discussion**

This study has extended previous research by looking at what patients with OA expect in regard to their disease course by examining short (1-year) and long term (5-year) expectations of future symptoms, disability and QoL. On the whole participants were found to be positive about their future health, expecting either the same or reduced amounts of pain, stiffness and the same or improved functionality both in the short and long term.

The findings indicate that patient's expectations about their health and well-being in 1 year's time was not predicted by current self-reported assessments of health status. In contrast they were associated with a number of cognitive and psychological variables, including dispositional optimism, a perceived sense of cure/control and behavioural disengagement. Whereas longer-term expectations were predicted by higher levels of current pain, an expectation of future surgery, valuing ones health more and a belief that OA can be

cured or at least controlled. These expectations are particularly interesting for patients with OA since the course of the condition is frequently punctuated by surgical intervention.

Expecting future surgery was one of the strongest predictors of positive expectations in relation to all 3 symptoms. Surgery in OA is performed only on those patients suffering with the most severe form of the condition who have failed to respond to other interventions (Dieppe et al., 1999). It could be that those patients who had the most positive 5-year pain expectations were in most need of surgery and although they were currently experiencing increased pain, the belief that they would be undergoing surgery gave them an increased sense of control over their disease leading to more positive expectations about the future.

This study highlights the role of optimism, beliefs about the cure and controllability of OA and behavioural disengagement in short term expectations. Being more optimistic, feeling more in control of one's arthritis with a belief that the disease is curable and using behavioural disengagement as a coping strategy predicts more positive 1-year expectations. These findings are consistent with earlier research which demonstrates the importance of dispositional optimism in the well-being of patients with OA (Ferreira & Sherman, 2007).

It is apparent, therefore, that patient beliefs and attitudes are critical in terms of their expectations about outcomes. In order to encourage feelings of optimism and control consultants could broaden the scope of the consultation to encompass not just the clinical aspects of the condition but also the patients' beliefs, experiences and attitudes. Perhaps by outlining the options and likely outcome of treatment, and eliciting patient expectations about the management of the condition, including previous approaches and experiences thereby making the patient feel more optimistic and in control of their arthritis.

This study is limited by the reductive nature of the expectation scores used in the regression analysis. In calculating expectation scores both the magnitude and direction of the expectations were retained,

although as mentioned earlier this entailed a loss of all concordant data (i.e. those participants who expected no change in their symptoms). Due to the limited sample size it was not possible to examine predictors of concordant data. Practicalities limited the sample size. As this was a pilot study the intention was to recruit between 75 and 156 participants. Other limitations in this study included participants who were predominantly white, attending secondary care and therefore likely to have more advanced OA, recruited from only one hospital and the inclusion of both hip and knee patients. No data was collected in relation to the particular joints affected by OA, outcomes of which are often quite different. In addition the less than optimal internal reliability of the IPQ cure/control and COPE behavioural disengagement subscale means these results should be interpreted with caution.

## **Conclusions**

This study shows how future expectations deviate from current assessments of health status largely in a positive direction. It also suggests that expectations of surgery, an optimistic disposition and beliefs about OA contribute to positive expectations in patients with OA. Further work on larger samples is required to overcome some of the limitations in the present study. Future work should address the possible influence of such expectations on future health outcomes and further explore directions of evidence-based management of such expectations.

Managing patient expectations have proved significant in predicting health outcomes in a wide range of conditions and may be a key component to the long-term care of patients. This study demonstrates the importance of examining patient coping styles, self-assessed pain levels, expectations about future surgery and to a lesser degree perceptions about OA. It highlights the potential importance of identifying and managing patient expectations at each consultation in order to arrive at a shared and agreed understanding of a continuing treatment plan between patients and clinicians.



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**Table 1.** Mean (M), standard deviation (SD) and paired t-test of current (CA) and future positive expectations

		<b>M (SD)</b>	<b><i>t</i></b>	<b>Eta<sup>2</sup></b>
<b><i>1yr expectations<sup>a</sup></i></b>				
<b>Pain</b>	CA 1yr	9.08 (4.29) 6.39 (5.38)	-4.75*	0.22
<b>Stiffness</b>	CA 1yr	3.48 (1.94) 2.61 (2.19)	-4.18*	0.18
<b>Function</b>	CA 1yr	30.61(16.22) 22.21(18.34)	-4.59†	0.21
<b><i>5 yr expectations<sup>b</sup></i></b>				
<b>Pain</b>	CA 5 yr	9.17 (4.22) 5.65 (5.43)	-5.83*	0.31
<b>Stiffness</b>	CA 5 yr	3.49(1.94) 2.32 (2.21)	-4.69*	0.23
<b>Function</b>	CA 5 yr	30.96(15.67) 20.48(18.05)	-4.88*	0.24

\* p <0.001; † p<0.0001; <sup>a</sup>, n=80; <sup>b</sup>; n=75

**Table 2.** Univariate logistic regressions: predictors of positive expectations

		<b>B</b>	<b>S.E.</b>	<b>Wald</b>	<b>Sig.</b>	<b>Odds Ratio</b>
<b>1yr expectations</b>						
<b>Pain</b>	IPQ Cure/control	1.43	.70	4.185	.04	4.19
	LOT	.18	.08	5.492	.02	1.19
	RSE	.19	.09	4.545	.03	1.21
<b>Stiffness</b>	COPE BD	-1.43	.66	4.664	.03	.24
<b>Function</b>	IPQ Cure/control	1.74	.71	6.033	.01	5.69
<b>5yr expectations</b>						
<b>Pain</b>	Expected Surgery	2.83	.77	13.496	.00	16.88
	COPE SD	.52	.26	4.133	.04	1.68
	IPQ Cure/control	1.84	.75	6.071	.01	6.29
	IPQ Timeline	-1.02	.45	5.218	.02	.36
	SF-36 SF	-.05	.02	4.519	.03	.96
	SF-36 BP	-.07	.03	4.937	.03	.94
	WOMAC pain	.15	.08	3.89	.05	1.16
<b>Stiffness</b>	Retired	1.45	.70	4.292	.04	4.25
	Relatives Health	1.55	.71	4.784	.03	4.73
	Expected Surgery	2.80	.81	12.024	.00	16.44
	HV	.14	.07	3.911	.05	1.15
	IPQ Control	1.79	.79	5.127	.02	6.00
	IPQ Timeline	-1.39	.57	5.816	.02	.25
<b>Function</b>	Retired	1.56	.59	6.935	.01	4.76
	Expected Surgery	2.38	.68	12.394	.00	10.75
	mHAQ	1.31	.66	3.881	.05	3.69
	IPQ Control	1.77	.65	7.356	.01	5.86
	IPQ Timeline	-1.01	.41	6.048	.01	.36
	SF-36 - PCS	-.05	.02	4.822	.03	.96
	SF-36 PF	-.05	.02	6.891	.01	.95
	SF-36 RP	-.04	.02	4.537	.03	.96
	SF-36 SF	-.05	.02	5.91	.02	.95
	SF-36 MH	-.06	.03	4.34	.04	.95
	SF-36 BP	-.09	.03	9.00	.00	.92
	VAS Pain	.03	.01	7.07	.01	1.03
	VAS Fatigue	.02	.01	4.63	.03	1.02
	WOMAC – pain	.16	.07	5.14	.02	1.17
	WOMAC – function	.05	.02	6.80	.01	1.05

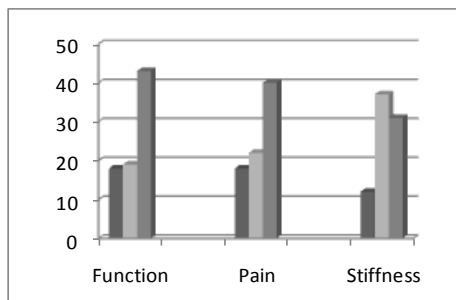
df = 1

SF, social functioning; BP, bodily pain; PF, physical functioning; RP, role physical; MH, mental health; SD, self distraction; BD, behavioural disengagement

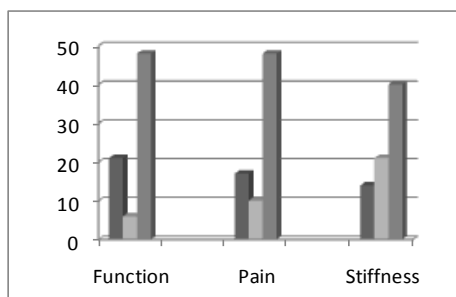
**Table 3.** Multivariate logistic regressions predicting positive expectations

		<b>B</b>	<b>SE</b>	<b>Wald</b>	<b>p</b>	<b>Odds Ratio</b>	<b>95% C.I</b>	
							<b>Lower</b>	<b>Upper</b>
<b><i>1- year expectations</i></b>								
<b>Pain(n=58)</b>	Optimism	0.18	0.08	5.49	0.02	1.19	1.03	1.38
<b>Stiffness (n=43)</b>	COPE BD	-1.43	0.66	4.66	0.03	0.24	0.07	0.88
<b>Function (n=60)</b>	IPQ cure/control	1.74	0.71	6.03	0.01	5.69	1.42	22.81
<b><i>5-year expectations</i></b>								
<b>Pain (n=65)</b>	Surgery	3.25	0.96	11.46	0.00	25.70	3.92	168.43
	IPQ cure/control	1.98	0.92	4.58	0.03	7.22	1.18	44.18
	SF-36 BP	-0.10	0.04	5.49	0.02	0.91	0.84	0.99
<b>Stiffness (n=49)</b>	Surgery	3.35	1.00	11.15	0.00	28.54	4.00	204.05
	Health Value	0.22	0.09	5.39	0.02	1.24	1.03	1.49
<b>Function (n=69)</b>	Surgery	2.65	0.86	9.63	0.00	14.18	2.66	75.75
	IPQ cure/control	2.22	0.86	6.68	0.01	9.24	1.71	49.90
	SF-36 BP	-0.12	0.04	9.59	0.00	0.88	0.82	0.96

df = 1; BP, bodily pain; BD, behavioural disengagement



**Figure 1:** Diagrammatic representation of 1-year Expectation Scores (n=80)



**Figure 2:** Diagrammatic representation of 5-year Expectations Scores (n=75)

**Key:** Y axis = Number of patients; X axis = symptoms; dark grey bars = negative expectations; light grey bars = expectations and assessment are the same; medium grey bars = positive expectations