

Development of a Rheumatology-specific Patient Concerns Inventory (PCI) and its use in the Rheumatology outpatient clinic setting

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Abstract

Objectives

Successful management of rheumatic conditions involves increasing complexity of care. Delivering this in a holistic way is a growing challenge. The aim of this study was to develop a Patient Concerns Inventory (PCI) and assess it in the Rheumatology clinic setting.

Methods

This observational exploratory study occurred with two phases. Phase 1: the PCI was developed after systematic literature search, expert opinion and three patient focus group discussions. Phase 2: the PCI was piloted in a general Rheumatology clinic.

Results

Fifty-four patients were assessed in the pre-PCI group and 51 in the post-PCI group. Median (IQR) duration of consultation was 8 (5-14) minutes without PCI and 15 (10-20) minutes with PCI. The pre-PCI group raised 335 concerns from 50 patients, median (IQR) of 5 (3-10) per patient, rising post-PCI to 521 concerns, median (IQR) of 9 (5-16) from 51 patients, $p=0.002$. Additional concerns predominantly arising from 'Physical and functional well-being' and 'Social care and wellbeing' domains. Most patients rated their experience with their doctor in the consultation as excellent or outstanding across all 11 questions in the questionnaire, both before and after the introduction of the PCI to the clinic setting.

Conclusion

The PCI is a useful holistic needs assessment tool for Rheumatology clinics. Although its use may initially prolong the consultation slightly, patients can raise a significantly higher number of concerns that do not occur at the expense of patient satisfaction. This may help in identifying areas of 'unmet need', which previously went unnoticed.

Key messages

- 1) Patient concerns inventory (PCI) is a useful holistic needs assessment tool in Rheumatology clinics.
- 2) The PCI is able to highlight important areas of unmet needs in Rheumatology clinics.
- 3) The use of PCI enables patients to ask more questions which may lead to greater patient satisfaction.

Background

Rheumatology services deal with a wide range of conditions that include inflammatory arthritis, osteoarthritis and connective tissue disorders, all of which may have profound detrimental effects on the quality of life. The care of Rheumatology diseases has improved considerably over the last few decades, with advent of biological agents¹⁻⁷, establishment of registries and development of protocolized, target-driven disease management pathways. The net effect is to encourage early identification and manage disease as dynamically and actively as possible⁹⁻¹⁰. As a result of this paradigm shift and increasing financial pressures worldwide, patient encounters have become more pressured, with less time for interaction.

As rheumatic conditions tend to run a long term course, the need for a holistic approach is essential if the many different issues that patients may encounter^{11, 12}, including pain, reduced function, loss of independence, fertility, appearance and psychological issues are to be adequately addressed. Some problems are potentially difficult, or embarrassing to talk about and therefore may be under-reported and under-recognised^{13,14}. This problem can be compounded in a busy clinic, where the clinician, who may be a doctor, nurse, physiotherapist or occupational therapist, might not have the time to take an exhaustive history. It would therefore be advantageous to have a system in place that allows the patient and clinician to focus specifically on issues that are most relevant to the patient at that particular time.

Such a problem is not unique to Rheumatology. Rogers et al developed a 'Patient Concerns Inventory (PCI)' for use in patients with head and neck cancer¹⁵. The purpose of the PCI is to provide patients with a list of potential concerns, which they highlight shortly before their consultation, thereby assisting the clinician to focus on and address those issues that were most relevant to the individual patient. The ultimate aim is to improve efficiency of the consultation and patient satisfaction. Experience from the head and neck cancer PCI indicates that this is a feasible and effective tool for use in the outpatient setting¹⁶⁻²⁵. A PCI was also piloted for the Neuro-Oncology setting²⁶. The outcomes from that study showed that patient satisfaction was high and that the PCI was able to address many issues that were not covered by other general cancer needs assessment tools. A similar study of 21 patients was carried out in Breast Oncology²⁷, where the PCI was able to identify 121 items of unmet need in patients with breast cancer.

There are many self-reported questionnaires already in use in Rheumatology such as RA-QoL (Rheumatoid Arthritis – Quality of life), BASDAI (Bath Ankylosing Spondylitis Disease Activity Index), BASFI (Bath Ankylosing Spondylitis Functional Index), AS-QoL (Ankylosing Spondylitis Quality of life), ASDAS (Ankylosing spondylitis Disease Activity Score), DAS-28 (Disease Activity Score for Rheumatoid arthritis), Visual Analogue Scale (VAS) and HAQ (Health Assessment Questionnaire) scores²⁸⁻³⁰. However, most of these are disease-specific and used to monitor disease activity or therapeutic response. Other scores are problem-specific, such as HAQ (physical activity) and VAS (pain). While there has been considerable effort invested in developing and measuring patient reported outcomes (PROMs) for rheumatic diseases, these have not been linked directly with patient concerns, which have rather been implied and not prospectively identified. We therefore set out to develop a tool that could allow a holistic needs assessment to be undertaken efficiently and effectively in the Rheumatology and which could subsequently inform the future design and interpretation of PROMs.

Methods

In phase I, a Rheumatology specific PCI was developed, making use of literature, expert opinion from healthcare professionals and patient focus groups. In phase II, the PCI was piloted in a representative general Rheumatology outpatient clinic, analysing patient satisfaction and length of consultation.

Phase I: Development of a Rheumatology Specific PCI

A literature review was conducted to identify issues relevant to patients with musculoskeletal diseases. Searches used databases SCOPUS, PubMed and ISI Web of Knowledge. The initial search focused on finding papers that discussed unmet needs in Rheumatology and to ascertain whether any similar tools had been developed in the Rheumatology setting (Supplementary Data, appendix 1). A further search looked for papers that used any HRQoL (Health-Related Quality of life) measured within the Rheumatology setting. Papers were selected on their titles and compatibility with inclusion and exclusion criteria. Search terms were charted to subject headings. Abstracts of relevant papers were read and, when appropriate, full papers accessed. Subsequently, any relevant concerns within accessed HRQoL tools were extrapolated.

Second, 19 clinical specialists, comprising Rheumatology consultants, Rheumatology postgraduate trainees, Rheumatology specialist nurses, physiotherapist, occupational therapist, pharmacist, general medical trainees and an Orthopaedic surgeon were consulted about issues they considered most important to their patients. They were also given the task of further refining the list of PCI items from the literature review.

Third, 3 patient focus groups provided feedback regarding the PCI, with patients from Rheumatology outpatient clinics at Aintree University Hospital. Patients that attended the clinic between February and April 2013 were given information about the study and asked if they would like to participate in the focus groups. All patients visiting the clinic during the recruitment period were invited to attend with no exclusions. 17 patients expressed an interest in being involved in the Focus groups. 16 (n=4, 5 and 7) patients attended focus groups, with one patient not attending. The age range was from 46-70 years, with 7 male and 9 females. The focus groups were held in March and April 2013 in the hospital where the clinic was based. To encourage candour two non-clinical researchers (M.O and J.K., Edge Hill University), who were not associated with the Rheumatology clinic, facilitated the focus groups.

Participants had previously been given an information sheet about the study and were also given a copy of the PCI categories at the beginning of the focus group. The facilitators asked that participants to consider four questions when discussing each item to help aid the framing of their discussions:

- (1) Is this something that might concern you or be important to you, either now or in the past or the future?
- (2) Is this something that you might want to talk to your doctor or other healthcare professional about?
- (3) Do you think that this item should be on the PCI?
- (4) What do you think about the wording of this item?

Patients were encouraged to discuss each item on the PCI list and the four questions were used as prompts if required. Patients were also asked to consider if they felt there were any items that should have been included on the PCI that were missed and to comment on the structure of the PCI.

Written informed consent was obtained. The discussions were digitally recorded and the researchers made notes throughout, encouraging participants to clarify any ambiguous comments and guiding them through the items of the PCI.

Focus group data were analysed using an adapted framework analysis approach (Ritchie & Spencer, Furber)^{40,41}, a robust and comprehensive method allowing researchers to systematically work through the data collected. This first involved researchers (M.O and J.K) immersing themselves in the data in order to develop an idea of the main discussion points around each area on the PCI. Accordingly they listened to focus group recordings and they read and re-read verbatim transcriptions and the notes made at each focus group. Researchers used the draft PCI as a basis of the framework and tabulated overall responses to each point on the PCI for each focus group. As the objective of the focus group was very specific and conversation was kept to points on the PCI, indexing and charting the data was a relatively easy process utilising the table produced in the framework stage of analysis. The data were synthesised by checking the framework chart against the original data sources to ensure proper recording of focus group opinion, which was summarised to give a clear overall opinion of each focus group and to incorporate any suggested comments.

Fourth, the same panel of clinical specialists were asked to split the PCI into four domains using the Delphi technique: Physical and functional well-being, Treatment related concerns, Social care and well-being, Psychological, emotional and spiritual well-being.

Phase II: Pilot Study of the Rheumatology PCI

The study was approved by the National Research Ethics Service (NRES) Northwest ethics board (REC reference 12/NW/0312). The PCI from Phase I was piloted in a consultant-led general Rheumatology clinic over a six month period between July and December 2013. All patients attending the clinic were eligible. Study awareness was raised using a poster on the clinic notice board. Before appointment, patients were sent an information sheet about this study. All patients were approached by research nurses before their clinic appointment and those who agreed to participate provided informed written consent. Demographic data was collected using electronic patient records (EDMS). The study design involved comparison of two different cohorts, one attending clinic prior to the introduction of the PCI (Pre-PCI cohort,) and the other attending clinic after the introduction of the PCI (Post-PCI cohort).

Pre-PCI patients attended for their clinic appointment as normal and were not asked to fill in the PCI. A research nurse sat in clinic as an observer and ticked all the items on the PCI that were discussed without the patient having any knowledge of the PCI. For all patients the length of the consultation was recorded in minutes and after the consultation patients were asked to fill in a brief questionnaire about their satisfaction with the consultation. Data was also collected regarding the number and nature of referrals made and HAQ scores. Patient satisfaction was evaluated using an 11-item questionnaire devised by the Royal College of General Practitioners⁴¹. This questionnaire is used as a tool for assessing the performance of GP trainees, by providing a measure of the patient's opinion of the doctor's communication and empathy during a consultation. Patients were asked to rate 10 specific components, as well as overall satisfaction, using a seven-point Likert scale. Post-PCI, patients were asked to complete the PCI whilst in the waiting room before their clinic appointment and their

responses on the PCI were passed to the consultant before the consultation began. All items selected by these patients were then addressed during the consultation.

The Mann-Whitney test was used to compare pre and post PCI groups in the number of PCI concerns, the Likert type questions on patient satisfaction, and also in respect of age, duration of illness, HAQ scores and duration of consultation. The mean score over all patient satisfaction questions was also compared. The Mann-Whitney test was similarly used to compare males and females. Fisher's exact test was used to compare pre and post PCI groups in regard to sex, onward referral and specific PCI concerns. Spearman's correlation coefficient (r_s) was used to quantify the correlation between age, duration of illness, HAQ score, duration of consultation, number of PCI items and patient satisfaction.

Results

Phase I: Development of a Rheumatology Specific PCI

The first search (appendix 1) produced only eight relevant papers³¹⁻³⁸, reflecting the present paucity of literature on unmet needs in Rheumatology. The second (appendix 1) produced many papers on the use of HRQoL measures within Rheumatology: most with only one HRQoL questionnaire and then used as secondary outcome measure. Kalyoncu et al³⁹ discussed the use of HRQoL tools within 109 Rheumatology papers, published between 2005 and 2007, including frequency of use. We attempted to access all the HRQoL tools highlighted within this review.

The clinical specialist assessment of potential patient concerns from the literature search led to the generation of a list of 38 potential concerns, which after discussions in patient focus groups led to a refined PCI comprising 39 items, which were distributed into 4 cognate domains, which corresponded to those for other PCIs.

Phase II: Pilot Study of the Rheumatology PCI

Full details listing broad demographics and diagnoses for 54 patients in the pre-PCI group and 51 patients in the post-PCI group are shown in Table 1. Nineteen per cent (10/54) of the pre-PCI and 24% (12/51) of the post PCI group had newly diagnosed disease. Twenty four per cent (13/54) of the PCI group had their diagnosis established more than 10 years previously compared to 53% (27/51) of the post-PCI group. Pre-PCI patients had lower HAQ scores than those in the post-PCI group (Table 1). Median (IQR) duration of consultation without PCI was 8 (5-14) minutes and with PCI was 15 (10-20) minutes. Two patients (4%) in the pre-PCI group required referrals to other specialties whereas no post-PCI patient required onward referral, $p=0.50$. Both groups lived with a variety of rheumatic conditions (Table 1).

A total of 335 concerns were raised in the pre-PCI group from 50 patients, median (IQR) of 5 (3-10) per patient, rising to 521 concerns, median (IQR) of 9 (5-16) from 51 post-PCI patients, $p=0.002$. This rise was noted predominantly from within the 'Physical and functional well-being' and 'Social care and wellbeing' domains (Table 2). In the 'Physical and functional well-being' domain the pre-PCI median (IQR) of 2 (0-4) and total 140 concerns rose to a post-PCI median (IQR) of 5 (2-8) and total 247 concerns, $p<0.001$. Particular concerns more frequently discussed after the PCI was introduced related to poor mobility, poor hand function, poor sleep, lack of energy and poor range of joint movement. For the 'Social care and wellbeing' domain the pre-PCI median (IQR) of 0 (0-1) and total 16 concerns rose to a post-PCI median (IQR) of 1 (0-2) and total 71 concerns, $p<0.001$. Particular

concerns more often discussed with the PCI were concerned with it being hard to exercise, things to avoid, aids and adaptation / occupational therapy and difficulty with / needing assistance with activities of daily living. For the 'Treatment-related concerns' domain there was little difference between pre and post PCI groups overall, both with a median (IQR) of 2 (1-4) concerns and little difference in total number (123 and 128), $p=0.80$. There was also no significant difference, $p=0.48$, in regard to the 'Psychological, emotional and spiritual well-being' domain, both with a median (IQR) of 1 (0-2) concerns and total number 56 and 75. However it was noted that whilst after the introduction of the PCI there was more discussion regarding sexual relationships, difficulties with activities of interest and enjoyment of life/loss of social activities these were counterbalanced by less discussion about understanding of the patient's illness.

In the pre-PCI group only pain was discussed with more than half of patients (Table 2, Figure 1). Infrequently discussed concerns, i.e. with under 5% of patients, were 'surgery', 'need assistance with activities of daily living', 'lack of medical, nursing and/or social support', 'things to avoid', 'aids and adaptation/ occupational therapy', 'finance', 'hard to exercise', 'problems with driving', 'illegal drugs', 'enjoyment of life/ loss of social activities', 'access to support group', 'sexual relationship', 'difficulties with activities of interest such as gardening and other activities'. However, in the post-PCI group (Table 2, Figures 1&2), 'pain', 'joint stiffness', 'swollen and tender joints', 'poor mobility', 'poor sleep' and 'lack of energy' were discussed with more than half of patients whilst only 'illegal drugs' concern was discussed with fewer than 5% of patients. The proportion of patients reporting each concern in the post-PCI group is detailed in Figure 1.

The vast majority of patients rated their experience with their doctor in the consultation as being excellent or outstanding across all 11 questions in the questionnaire, both before and after the introduction of the PCI to the clinic setting (Table 3). There were nine consultations pre-PCI for which one or more of the responses to the 11 questions were less than 'very good' as compared to seven consultations post-PCI. Mean scores were slightly higher in the post-PCI group though, for none of the questions was there a statistically significant difference between the two sets (pre vs. post) of responses. The overall mean score (the mean of the responses across all 11 questions) was also slightly higher, median (IQR) of 6.18 (5.45-6.18) pre-PCI and 6.41 (5.68-7.00) post PCI, $p=0.65$.

Other analyses were performed to investigate the level of association between the baseline variables of age, gender, HAQ score and duration of illness with length of consultation, patient satisfaction and the number of PCI items. Both pre and post PCI groups were combined for these analyses. No statistical association was seen at $p<0.01$ between any of these baseline variables and duration of consultation, nor between age or duration of illness with either the number of PCI items or with patient satisfaction. There was however significant correlation between HAQ score and the number of PCI items with higher HAQ scores tending to go with a greater number of PCI concerns in the 'Physical and functional well-being' domain ($r_s=0.34$, $p=0.004$), the 'Treatment related concerns' domain ($r_s=0.27$, $p=0.02$) and total number ($r_s=0.34$, $p=0.003$) but not with the other two domains ($r_s=0.03$ and $r_s=0.00$ respectively). There were also negative correlations of borderline significance with the patient satisfaction questions ranging from $r_s=-0.28$ to $r_s=-0.14$, median $r_s=-0.25$, and with the overall mean patient satisfaction score $r_s=-0.25$, $p=0.05$, indicating the tendency for higher HAQ scores to go with lower (worse) satisfaction scores. These correlations involving HAQ scores were generally 'weak' but as HAQ score seems to be a potential confounder to the comparisons made between pre and post PCI groups the results were stratified and are shown in Table 4. The tendency remains towards having more PCI concerns post PCI for HAQ scores between 0.50 and 0.99, for scores of 1.00 and above and for when scores were not known, and there were too few scores below 0.50 in the post-PCI group to pass comment. There was also a consistent trend towards greater satisfaction post-PCI for HAQ scores 0.50-0.99 and of 1.00 and above.

Duration of consultation was also associated with the number of PCI items in three of the four domains and overall, $r_s=0.36$ overall $p<0.001$. There was a median of 5 concerns for consultations under 10 minutes, 7 when 11-19 minutes and 10 when longer than 20 minutes. Amongst the baseline variables gender was associated with HAQ scores, $p=0.001$ with females having lower HAQ scores (median 0.38 vs. 0.88). Duration of illness was also associated with HAQ score, $r_s=0.32$, $p=0.006$. Median HAQ score was 0.44 for duration 0-1 years, 0.75 for 2-9 years and 0.88 for 10 or more years. Duration of illness was also associated with age, $r_s=0.44$, $p<0.001$.

Discussion:

We have developed a novel instrument with potential utility across a whole range of rheumatological conditions. It is able to facilitate the identification of concerns that patients may have, but perhaps not be able to otherwise raise with their clinician. Our data demonstrated that, despite the overall longer duration of illness and higher mean HAQ scores, the patient satisfaction in the post PCI group remained high. This may, in part at least, be due to the fact that patients in the post PCI group asked significantly more questions and discussed a greater number of concerns compared to the pre-PCI group (see table 2). It has previously been demonstrated that patient satisfaction increases significantly when interventions are designed to encourage patients to ask questions⁴³. The fact that the baseline patient satisfaction in this particular clinic was so high unfortunately meant that it was not practical to detect significant changes in satisfaction after implementation of the PCI. We are now in the process of evaluating it across other clinics.

Although the mean duration of consultation increased slightly for the post-PCI group, it is important to remember that the PCI was able to identify a significantly higher number of items of unmet need, mainly from the 'Physical and functional well-being' and the 'Social care and well-being' domains (table 2). This was due to the fact that PCI provided patients the opportunities to discuss potential problems such as sexual relationships, difficulties with activities of interest and enjoyment of life and loss of social activities, amongst others. These were clearly important concerns for many patients that they had hitherto been unable to discuss, despite access to primary care doctors, Rheumatology nurse advice-lines and Rheumatology clinics. Part of the problem might lie in the patients' perceived acceptability of asking certain questions. However, this would appear to become easier when potential specific concerns are presented on a checklist and is more reassuring for the patient that it is appropriate to ask such questions. Thus, PCI provides an opportunity to improve doctor-patient communication. Additionally, the PCI also serves as a visual aid for both doctors and patients, reminding them about the different aspects of care thus becoming a novel and powerful tool for holistic needs assessment.

There are a number of potential limitations to this study. Whilst we took great pains to devise a list of concerns from literature search, expert opinion and also focus groups, it is possible that important potential concerns were missed. This can be addressed as the tool is used more widely. We also evaluated the instrument in only one clinic – however, we believe that the number of patients studied was sufficient to detect the initial changes that we set out to evaluate and determine if it was an appropriate tool to roll out further. We felt that there were also advantages of consistency if initially studies used only one clinician. Finally, the difference in disease duration between the two groups might have potentially led to a difference in needs. Indeed, understanding possible changes of needs with time is a focus for future work with this tool.

We believe that the PCI is a useful holistic needs assessment tool in Rheumatology clinics, where it can highlight important areas of unmet need. Our study demonstrates that, with the use of PCI,

patients are able to discuss a significantly higher number of concerns that would otherwise go unrecognised when the traditional consultation style is used. While Rheumatologists may not be able to deal with all the concerns directly or even during the same appointment, this should prompt appropriate referrals with suitable follow-up to ensure the concerns are adequately addressed.

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Table 1. Age, sex, duration of illness, diagnosis, duration of consultation, HAQ scores and onward referral for the two groups of patients before and after the introduction of the PCI.

	Pre-PCI group (n=54)	Post-PCI group (n=51)
Sex, male: female, n	17:37	11:40
Age, mean (SD), years	53 (16)	56 (16)
*Duration of illness, median (IQR), years	3 (1-9)	10 (2-13)
Diagnosis (n)		
Rheumatoid arthritis	19	22
Not established	14	6
Systemic sclerosis	1	0
Polymyalgia rheumatica	1	1
Stills disease	1	1
Gout	2	0
Unspecified inflammatory arthritis	1	1
Ankylosing spondylitis	1	0
Granulomatosis with polyangiitis	2	0
Fibrodysplasia ossificares progressiva	1	0
Sjogrens syndrome	2	2
Behcet's syndrome	1	0
Osteoarthritis	1	2
Palindromic rheumatism	1	0
Psoriatic arthritis	1	5
Fibromyalgia	1	0
Pauci articular arthritis	1	0
*Systemic lupus erythematosus (SLE)	1	8
Reactive arthritis	1	0
Myositis	1	0
Seronegative spondyloarthritis	0	1
Juvenile idiopathic arthritis (JIA)	0	1
Inflammatory monoarthritis	0	1
***Duration of consultation, median (IQR), minutes	8 (5-14), n=51	15 (10-20), n=50
HAQ scores, median (IQR), n	0.44 (0.13-0.97), n=40	0.88 (0.56-1.00), n=33
Referrals to other specialties, n	2	0

*0.01 ≤ p < 0.05, **0.001 ≤ p < 0.01, ***p < 0.001

Table 2. Concerns discussed by patients, before and after the introduction of the PCI to the clinic setting

Domain	Specific concern	Highlighted Pre-PCI (n=50*)	Highlighted Post PCI (n=51)	P value**
D1: Physical and functional well-being	Pain	36	34	0.67
	Joint stiffness	24	34	0.07
	Swollen and tender joints	25	28	0.69
	Joint deformity	10	14	0.48
	Poor range of joint movement	11	22	0.03
	Poor mobility	8	26	<0.001
	Poor hand function	9	24	0.003
	Poor sleep	8	33	<0.001
	Lack of energy	9	32	<0.001
	Total concerns	140	247	
D2: Treatment related concerns	Disease progression	18	21	0.68
	Treatment side effects	24	15	0.07
	Weight changes with treatment	4	11	0.09
	Drug interactions	9	14	0.34
	Treatment ineffective	10	9	0.80
	Surgery	2	6	0.27
	Continuity of care (seeing different doctors each time)	9	8	0.80
	Blood tests and other investigations you wanted to discuss	22	21	0.84
	Information on what to do in a flare-up situation	16	16	>0.99
Access to doctors/ nurses	9	7	0.60	
	Total concerns	123	128	
D3: Social care and well-being	Need assistance with activities of daily living	1	8	0.03
	Difficulty with activities of daily living such as caring for self, dressing and house work	6	15	0.05
	Lack of medical, nursing and/or social support	0	3	0.24
	What to avoid	0	6	0.03
	Aids and adaptation/ occupational therapy	2	10	0.03
	Finance	0	5	0.06
	Hard to exercise	0	16	<0.001
	Problems with driving	0	3	0.24
	Work and employment	7	4	0.36
Illegal drugs	0	1	>0.99	
	Total concerns	16	71	
D4: Psychological, emotional and spiritual well-being	Anxiety/ depression	6	13	0.13
	Enjoyment of life/ loss of social activities	2	12	0.008
	Worry of the future	3	9	0.12
	Understanding my illness	24	9	0.001
	Access to support group	1	3	0.62
	Sexual relationship	0	5	0.06
	Self-esteem	9	9	>0.99
	Difficulties with activities of interest such as gardening and other activities	1	8	0.03
	Are you concerned about the accuracy of your diagnosis	10	7	0.44
	Total concerns	56	75	

*Observational data were not available for 4 of the 54 pre-PCI patients

**Fishers exact test

Table 3. Patient satisfaction *Mann-Whitney test

In your consultation today how good was your doctor at:		Poor to Fair (1)	Fair (2)	Fair to Good (3)	Good (4)	Very Good (5)	Excellent (6)	Outstanding (7)	Total cases	P Value*	Mean score
Q1: Making you feel at ease? (being friendly and warm towards you, treating you with respect; not cold or abrupt)	Pre-PCI	1	1	-	3	5	16	24	50	0.33	6.08
	Post-PCI	-	-	-	-	4	20	26	50		6.44
Q2: Letting you tell "your" story? (giving you time to fully describe your illness in your own words; not interrupting or diverting you)	Pre-PCI	1	1	-	3	9	14	23	51	0.93	5.98
	Post-PCI	-	-	-	3	7	20	20	50		6.14
Q3: Really listening? (paying close attention to what you were saying; not looking at the notes or the computer as you were talking)	Pre-PCI	1	2	-	3	9	12	24	51	0.60	5.92
	Post-PCI	-	-	-	2	8	17	23	50		6.22
Q4: Being interested in you as a whole person? (asking/knowing relevant details about your life, your situation; not treating you as "just a number")	Pre-PCI	2	1	-	5	6	13	22	49	0.31	5.84
	Post-PCI	-	-	-	3	6	16	25	50		6.26
Q5: Fully understanding your concerns? (communicating that he/she had accurately understood your concerns; not overlooking or dismissing anything)	Pre-PCI	1	2	-	-	11	15	22	51	0.60	5.96
	Post-PCI	-	-	-	4	9	12	25	50		6.16
Q6: Showing care and compassion? (seeming genuinely concerned, connecting with you on a human level; not being indifferent or "detached")	Pre-PCI	2	-	-	4	7	16	22	51	0.44	5.94
	Post-PCI	-	-	-	1	11	13	25	50		6.24
Q7: Being positive? (having a positive approach and a positive attitude; being honest but not negative about your problems)	Pre-PCI	1	1	-	5	8	13	23	51	0.40	5.92
	Post-PCI	-	-	1	1	11	11	26	50		6.20
Q8: Explaining things clearly? (fully answering your questions, explaining clearly, giving you adequate information; not being vague)	Pre-PCI	-	1	1	3	9	14	23	51	0.73	6.02
	Post-PCI	-	-	-	2	7	20	21	50		6.20
Q9: Helping you to take control? (exploring with you what you can do to improve your health yourself; encouraging rather than "lecturing" you)	Pre-PCI	2	-	-	5	7	14	22	50	0.95	5.90
	Post-PCI	-	-	-	6	5	19	20	50		6.06
Q10: Making a plan of action with you? (discussing the options, involving you in decisions as much as you want to be involved; not ignoring your views)	Pre-PCI	-	1	1	3	6	14	25	50	0.83	6.12
	Post-PCI	-	-	-	4	7	13	26	50		6.22
Q11: Overall, how would you rate your consultation with this doctor today?	Pre-PCI	1	1	-	2	6	13	28	51	0.38	6.18
	Post-PCI	-	-	-	1	7	11	32	51		6.45

Table 4. PCI concerns and patient satisfaction before and after the introduction of the PCI, stratifying for HAQ score.

Table shows Mean (N) values

		HAQ <0.50	HAQ 0.50-0.99	HAQ 1.00+	HAQ NK
PCI concerns					
Domain D1: Physical and functional well-being	Pre-PCI	2.35 (20)	3.40 (10)	3.10 (10)	2.00 (14)
	Post-PCI	2.20 (5)	4.73 (15)	6.62 (13)	4.39 (18)
Domain D2: Treatment related concerns	Pre-PCI	2.00 (20)	1.70 (10)	3.10 (10)	2.50 (14)
	Post-PCI	0.80 (5)	2.53 (15)	2.77 (13)	2.78 (18)
Domain D3: Social care and well-being	Pre-PCI	0.45 (20)	0.10 (10)	0.30 (10)	0.21 (14)
	Post-PCI	0.60 (5)	1.07 (15)	1.46 (13)	1.83 (18)
Domain D4: Psychological, emotional and spiritual well-being	Pre-PCI	1.05 (20)	1.20 (10)	1.10 (10)	0.86 (14)
	Post-PCI	0.60 (5)	1.40 (15)	1.69 (13)	1.61 (18)
Total concerns	Pre-PCI	5.85 (20)	6.40 (10)	7.60 (10)	5.57 (14)
	Post-PCI	4.20 (5)	9.73 (15)	12.54 (13)	10.61 (18)
Patient satisfaction Questionnaire					
Q1: Making you feel at ease?	Pre-PCI	6.61 (18)	6.00 (8)	5.10 (10)	6.14 (14)
	Post-PCI	6.60 (5)	6.53 (15)	6.42 (12)	6.33 (18)
Q2: Letting you tell "your" story?	Pre-PCI	6.47 (19)	6.13 (8)	5.10 (10)	5.86 (14)
	Post-PCI	6.20 (5)	6.20 (15)	6.25 (12)	6.00 (18)
Q3: Really listening?	Pre-PCI	6.47 (19)	5.88 (8)	5.10 (10)	5.79 (14)
	Post-PCI	6.00 (5)	6.47 (15)	6.17 (12)	6.11 (18)
Q4: Being interested in you as a whole person?	Pre-PCI	6.33 (18)	5.75 (8)	5.00 (9)	5.79 (14)
	Post-PCI	6.20 (5)	6.40 (15)	6.17 (12)	6.22 (18)
Q5: Fully understanding your concerns?	Pre-PCI	6.42 (19)	6.00 (8)	5.20 (10)	5.86 (14)
	Post-PCI	6.00 (5)	6.47 (15)	6.17 (12)	5.94 (18)
Q6: Showing care and compassion?	Pre-PCI	6.47 (19)	5.75 (8)	5.00 (10)	6.00 (14)
	Post-PCI	6.20 (5)	6.53 (15)	6.25 (12)	6.00 (18)
Q7: Being positive?	Pre-PCI	6.47 (19)	5.75 (8)	4.90 (10)	6.00 (14)
	Post-PCI	6.20 (5)	6.60 (15)	6.17 (12)	5.89 (18)
Q8: Explaining things clearly?	Pre-PCI	6.47 (19)	5.75 (8)	5.20 (10)	6.14 (14)
	Post-PCI	6.00 (5)	6.33 (15)	6.25 (12)	6.11 (18)
Q9: Helping you to take control?	Pre-PCI	6.37 (19)	5.75 (8)	4.90 (10)	6.08 (14)
	Post-PCI	6.00 (5)	6.20 (15)	6.08 (12)	5.94 (18)
Q10: Making a plan of action with you?	Pre-PCI	6.53 (19)	6.00 (8)	5.30 (10)	6.23 (14)
	Post-PCI	6.00 (5)	6.40 (15)	6.08 (12)	6.22 (18)
Q11: Overall, how would you rate your consultation with this doctor today?	Pre-PCI	6.58 (19)	6.38 (8)	5.30 (10)	6.14 (14)
	Post-PCI	6.60 (5)	6.53 (15)	6.23 (12)	6.50 (18)
Mean score	Pre-PCI	6.47 (19)	5.92 (8)	5.11 (10)	5.99 (14)
	Post-PCI	6.18 (5)	6.42 (15)	6.20 (12)	6.12 (18)

Figure 1 Percentage of participants discussing each concern item in the post-PCI group.

