

RESEARCH ARTICLE

Differences between Patient and Surgeon Interests in Musculoskeletal Research

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Abstract

Background: There is a growing interest in engaging patients in research priorities and project design. This study compared topics patients and surgeons would like to address in upper extremity musculoskeletal research.

Methods: We invited patients on social media-based support groups for specific musculoskeletal illnesses and members of the Science Of Variation Group to indicate the three most important research topics by disease. We also measured agreement that patients should participate in research on a five-point Likert scale. We categorized research priorities into the following categories: treatment, cause and natural history, recovery, diagnostic process, and economic impact. Bivariate analysis was used to detect differences between surgeons and patient responses. Multivariable regression models sought factors associated with agreement whether patients should participate in research. Sixty-two surgeons and 350 patients completed the survey, who had one of the following musculoskeletal illnesses: Dupuytren contracture, adhesive capsulitis, Kienböck disease, complex regional pain syndrome, rotator cuff tendinopathy, carpal- or cubital tunnel syndrome, and rheumatoid arthritis.

Results: Both patients and surgeons were most interested in research into treatment options. There were few differences in the number of responses per category between surgeons and patients. Patients and surgeons with fewer years of practice agree most with involving patients in research.

Conclusion: Patients and surgeons prioritize research about treatment. Surgeons were more interested in natural history of disease and surgical techniques, while patients were more interested in alleviation of pain.

Level of evidence: N/A

Keywords: Patient interests, Research topics, Science of variation group, Social media, Surgeon interests

Introduction

There is a growing interest in engaging patients in research projects, as demonstrated by the increasing number of initiatives that involve patients in identifying research priorities, research design, data collection, and identification of outcomes (1-7). A survey among researchers and patient delegates indicated that including patients in research projects may help broaden the research agenda, and may promote the measurement of outcomes that are relevant to patients' lives (8) publications and conference proceedings, followed by a responsive evaluation including 32 qualitative

semistructured interviews (SETTING: The international, biannual research conference OMERACT 10 (Malaysia, 2010.). An increasing number of scientific journals and research funding agencies encourage patient involvement and offer guidelines on how to accomplish a successful collaboration (9, 10). Such development may represent a paradigm shift that will make research more accessible and appealing to the public.

This study assessed topics patients would like to address in upper extremity musculoskeletal research, and whether these topics differ from those of a group of

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practicing orthopedic surgeons. We tested the primary null hypothesis that there is no difference in upper extremity research topics recommended by patients and surgeons. We tested the secondary hypothesis that there are no factors associated with the importance of including patients in research, accounting for sex, age, and geographic location.

Materials and Methods

Study design

Upon acquiring Institutional Review Board (IRB) approval, we approached patients on Facebook who were active in an online support group, who had one of the following musculoskeletal conditions: Dupuytren contracture, adhesive capsulitis, Kienböck disease, complex regional pain syndrome (CRPS), rotator cuff tendinopathy, carpal- (CTS) or cubital tunnel syndrome (CubTS), and rheumatoid arthritis (11-16). They were asked to participate in an anonymous online survey that inquired (1) which topics pertaining to their illness they found the most important in research of musculoskeletal care; and (2) how important it is to involve patients in different aspects of research (17).

Additionally, an invitation was sent to all members of the Science of Variation Group (SOVG). The SOVG holds a database of surgeons who are invited to participate in an online survey on a monthly basis, whose sole incentive is group authorship on the manuscript. Since there is a significant proportion of inactive members, it is not feasible to calculate a meaningful response rate. Members of the SOVG were asked to fill out the same survey as the patients, except surgeons were asked to summarize the most important research topics for all aforementioned conditions.

Survey Monkey (Palo Alto, CA, USA), an online tool used to design, distribute, and analyze surveys, was utilized to develop a questionnaire for the patients and surgeons (18). Participants were asked to fill out the three most important topics of research for a particular musculoskeletal condition in a text box. Consequently, they were asked to indicate their agreement with the following statements on a five-point Likert scale, ranging from 'Strongly disagree' to 'Strongly agree': 1) Patients should be involved in establishing research priorities; 2) Patients should be involved in deciding what to measure in research; 3) Patients should be involved in drafting research protocols; 4) Patients should be involved in drafting research manuscripts; 5) Patients should be involved in rating and prioritizing grant proposals. Additionally, demographic information was collected from all participants.

Patient and surgeon characteristics

Three hundred and fifty patients completed our survey. The vast majority of patients was female (288 [82%]), the largest group was between the age of 50 and 59, and was residing in North America [Table 1]. Sixty-two surgeons completed the survey, the majority of whom was male (93%), and was subspecialized in hand or wrist surgery [Table 1]. Most surgeons were practicing in North America, and had less than eleven years of experience.

| Table 1. Patient and surgeon demographics | |
|---|----------|
| Patient variables | Value |
| N | 350 |
| Male | 62 (18) |
| Age group | |
| 18-29 | 11 (3.2) |
| 30-39 | 23 (6.6) |
| 40-49 | 73 (21) |
| 50-59 | 127 (36) |
| 60-69 | 95 (27) |
| 70-79 | 20 (5.7) |
| Continent | |
| North America | 245 (70) |
| Europe | 76 (22) |
| Australia | 21 (6.0) |
| Other | 7 (2.0) |
| Diagnosis | |
| Dupuytren contracture | 198 (57) |
| Adhesive capsulitis | 76 (22) |
| Kienböck disease | 59 (17) |
| Complex regional pain syndrome | 8 (2.2) |
| Rotator cuff tendinopathy | 4 (1.1) |
| Carpal or cubital tunnel syndrome | 3 (0.9) |
| Rheumatoid arthritis | 1 (0.3) |
| Surgeon variables | Value |
| N | 62 |
| Male | 57 (93) |
| Years in practice | |
| 0-5 | 16 (26) |
| 6-10 | 16 (26) |
| 11-20 | 19 (31) |
| 21-30 | 10 (16) |
| Continent | |
| North America | 39 (64) |
| Europe | 11 (18) |
| Australia | 2 (3.3) |
| Other | 9 (15) |
| Subspecialty | |
| Hand and wrist | 42 (69) |
| Shoulder and elbow | 16 (26) |
| Other | 3 (4.9) |

Variables as number (percentage).

Statistical analysis

The most important topics of research, as listed by the participants, were categorized by the first author into one of the five following categories: treatment, cause and natural history, recovery, diagnostic process, and economic impact. Consensus on these categories was reached by analyzing and assigning themes to a subset of answers. Differences in topics of interest between patients and surgeons were determined with a chi-square test. Bivariate analysis was not performed for diagnosis groups where the number of patient participants was below twenty. We calculated a total score that indicated how interested participants were in involving patients in research by adding up the scores to each of the five questions, and dividing the sum by 2.5. This resulted in a score ranging from one to ten; with one indicating that the participant had no interest in involving patients in musculoskeletal research, while a score of ten indicated a lot of interest. Where appropriate, chi-square and Fisher's exact test were used to determine differences in scores between patient and surgeon subgroups. All variables with *P* values <0.10 were included in multivariable linear

regression analysis.

An a priori power analysis determined that 70 subjects in each diagnostic group would provide 80% statistical power, with alpha set at 0.05, for a chi-square test to find a 25% difference in the proportions of recommended research topics, assuming a proportion of 0.40 in group one and 0.65 in group two. Since there was great variety in the degree of activity between the patient support groups, and since data collection had slowed down substantially, the authors decided to terminate data collection prior to reaching this number for each diagnosis.

Results

Both patients and surgeons were most interested in research into treatment options for all musculoskeletal conditions [Tables 2; 3]. In bivariate analysis, there were no differences between surgeon and patient interests for the conditions adhesive capsulitis, Kienböck disease, and CRPS (*P*>0.05), and differences could not be determined for rotator cuff tendinopathy, CTS and CubTS, and rheumatoid arthritis. Surgeons were significantly more interested in the cause and natural history of Dupuytren

Table 2. What do patients want upper extremity research to address?

| Topics | Condition | | | | | | | total |
|--|---------------------|---------------------------|------------------------|------------------|-----------------------|----------------------|--------------------------------|-------|
| | Adhesive capsulitis | Rotator cuff tendinopathy | Carpal tunnel syndrome | Kienböck disease | Dupuytren contracture | Rheumatoid arthritis | Complex regional pain syndrome | |
| Treatment | 91 | 6 | 3 | 89 | 309 | 0 | 11 | 509 |
| Cause and natural history | 79 | 1 | 0 | 37 | 164 | 0 | 6 | 287 |
| Recovery | 24 | 0 | 0 | 19 | 35 | 0 | 1 | 79 |
| Diagnostic process | 3 | 2 | 0 | 9 | 21 | 0 | 0 | 35 |
| Economic impact | 0 | 0 | 0 | 1 | 2 | 0 | 0 | 3 |
| Total | 197 | 9 | 3 | 155 | 531 | 0 | 18 | 913 |
| Variables reported as number (percentage). | | | | | | | | |
| Chi2 (surgeon vs patient)= | 0.744 | ND | ND | 0.052 | 0.004 | ND | 0.489 | |

Table 3. What do surgeons want upper extremity research to address?

| Topics | Condition | | | | | | | total |
|--|---------------------|---------------------------|------------------------|------------------|-----------------------|----------------------|--------------------------------|-------|
| | Adhesive capsulitis | Rotator cuff tendinopathy | Carpal tunnel syndrome | Kienböck disease | Dupuytren contracture | Rheumatoid arthritis | Complex regional pain syndrome | |
| Treatment | 74 | 80 | 73 | 86 | 77 | 108 | 72 | 570 |
| Cause and natural history | 69 | 57 | 46 | 59 | 72 | 38 | 58 | 399 |
| Recovery | 14 | 15 | 19 | 10 | 9 | 3 | 9 | 79 |
| Diagnostic process | 3 | 7 | 19 | 6 | 1 | 11 | 21 | 68 |
| Economic impact | 0 | 2 | 7 | 0 | 2 | 0 | 1 | 12 |
| Total | 160 | 161 | 164 | 161 | 161 | 160 | 161 | 1128 |
| Variables reported as number (percentage). | | | | | | | | |
| Chi2 (surgeon vs patient)= | 0.744 | ND | ND | 0.052 | 0.004 | ND | 0.489 | |

disease, and were less interested in treatment options [Table 3].

In bivariate analysis, surgeons showed significantly less interest in involving patients in research than patients (5.8 ± 1.1 vs. 7.3 ± 1.4 ; $P < 0.001$; Table 4; Supplemental Figures 1 to 5). Patients in the age group 50-59, patients from Australia, and patients with CRPS were the most interested in getting patients involved in research. Surgeons who were five years in practice or

less, and surgeons who were subspecialized in hand or wrist surgery were most interested in getting patients involved [Table 4]. In multivariable linear regression analysis, the diagnosis Kienböck disease and the orthopedic subspecialty “hand or wrist surgery” were associated with higher interest in involving patients in research [Table 5]. Surgeons who were 21 to 30 years in practice had less interest in involving patients in research.

Table 4. Bivariate analysis of factors associated with agreement whether patients should be involved in research

| Participant | Involve Patients Score (0-10) | P value |
|-----------------------------------|-------------------------------|------------------|
| Surgeon | 5.8 ± 1.1 | <0.001 |
| Patient | 7.3 ± 1.4 | |
| Patient variables | | |
| All | 7.3 ± 1.4 | . |
| Gender | | 0.12 |
| Female | 7.4 ± 1.4 | |
| Male | 7.2 ± 1.3 | |
| Age group | | 0.064 |
| 18-29 | 7.2 ± 1.2 | |
| 30-39 | 7.4 ± 1.1 | |
| 40-49 | 7.4 ± 1.3 | |
| 50-59 | 7.5 ± 1.3 | |
| 60-69 | 7.2 ± 1.5 | |
| 70-79 | 7.0 ± 1.6 | |
| Continent | | <0.001 |
| North America | 7.3 ± 1.4 | |
| Europe | 7.2 ± 1.4 | |
| Australia | 7.7 ± 1.3 | |
| Other | 7.1 ± 0.8 | |
| Diagnosis | | <0.001 |
| Dupuytren contracture | 7.2 ± 1.4 | |
| Adhesive capsulitis | 7.4 ± 1.2 | |
| Kienböck disease | 7.7 ± 1.3 | |
| Complex regional pain syndrome | 7.9 ± 1.4 | |
| Rotator cuff tendinopathy | 6.2 ± 1.2 | |
| Carpal or cubital tunnel syndrome | 6.0 ± 0 | |
| Rheumatoid arthritis | - | |
| Surgeon variables | | |
| All | 5.8 ± 1.1 | . |
| Gender | | 0.75 |
| Female | 5.7 ± 1.6 | |
| Male | 5.8 ± 1.0 | |

| Table 4 Continued. | | |
|--------------------|------------|------------------|
| Years in practice | | 0.018 |
| 0-5 | 6.2 ± 1.1 | |
| 6-10 | 5.8 ± 1.3 | |
| 11-20 | 5.7 ± 0.94 | |
| 21-30 | 5.4 ± 0.97 | |
| Continent | | 0.50 |
| North America | 5.9 ± 1.0 | |
| Europe | 5.6 ± 1.3 | |
| Other | 5.7 ± 1.0 | |
| Subspecialty | | <0.001 |
| Hand and wrist | 6.0 ± 0.91 | |
| Shoulder and elbow | 5.3 ± 1.2 | |
| Other | 5.2 ± 1.8 | |

Bold indicates statistical significance, P < 0.10.

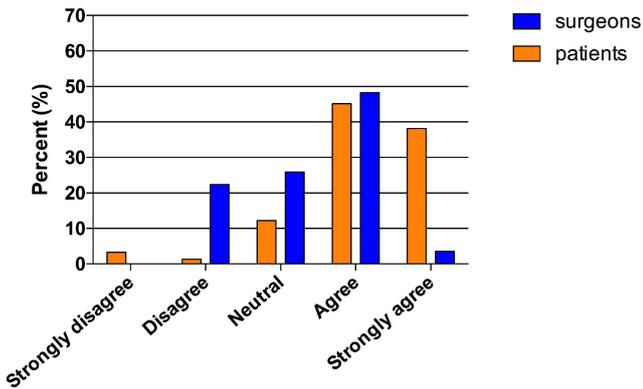


Figure 1. Surgeon and patient agreement whether patients should be involved in establishing research priorities.

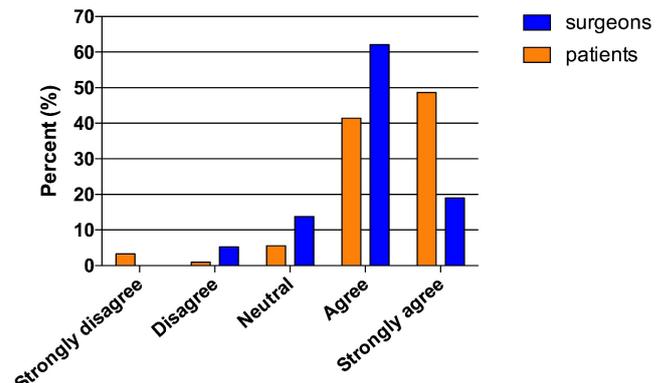


Figure 2. Surgeon and patient agreement whether patients should be involved in deciding what to measure in research.

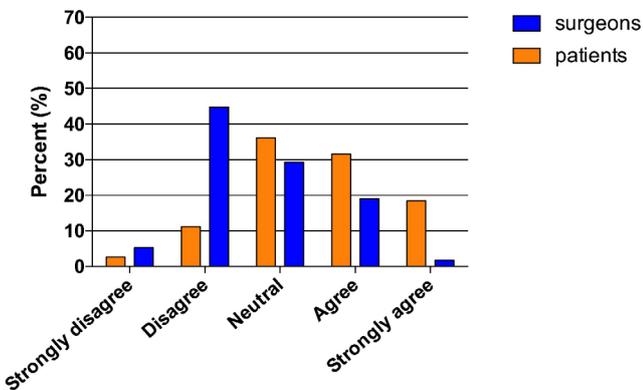


Figure 3. Surgeon and patient agreement whether patients should be involved in drafting research protocols.

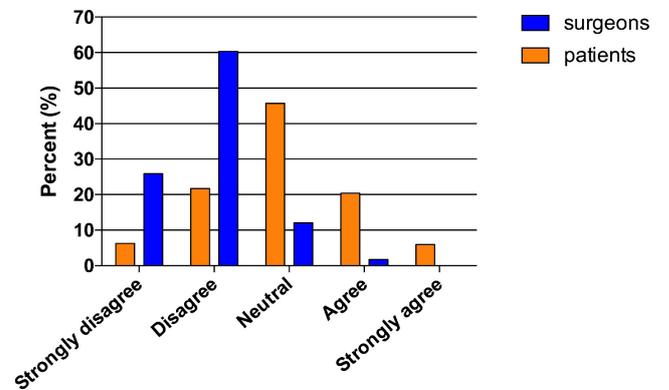


Figure 4. Surgeon and patient agreement whether patients should be involved in writing research manuscripts.

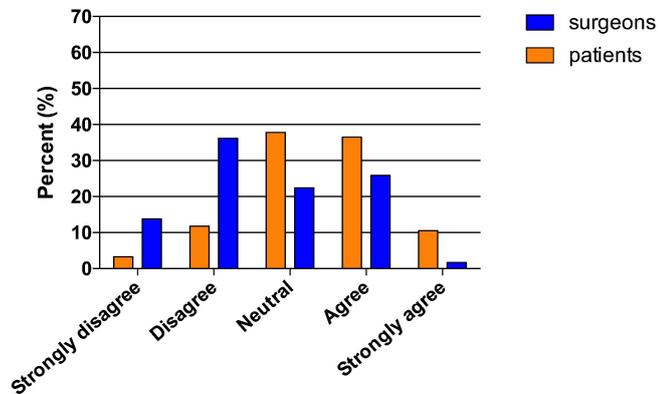


Figure 5. Surgeon and patient agreement whether patients should be involved in prioritizing grant proposals.

Discussion

There is an increasing number of research initiatives that involve patients in establishing research priorities,

designing studies, and identification of outcomes worth measuring (1, 4, 6, 7). We used online patient support groups to find motivated, knowledgeable patients and inquired about their priorities for research of their disease. Additionally, we asked them to rate how important they deem patient involvement in different aspects of scientific research. We compared patient responses to responses from an international group of orthopedic surgeons, and found that the three most important research topics did not differ substantially between patients and surgeons. Overall, patients were more open than surgeons to involving patients in scientific research. Surgeons who were in practice for longer and surgeons outside of hand and wrist surgery were less interested in involving patients.

This study should be read with the following limitations in mind. First, we did not have a sufficient number of patients for adequate power to detect differences in categories between surgeons and patients for the diagnoses rotator cuff tendinopathy, CTS and CubTS, and rheumatoid arthritis. It is important to note that the difficulty with data collection did not originate from an

Table 5. Multivariable linear regression analysis of factors associated with agreement whether patients should be involved in research

| Patient variables | Regression coefficient (95%-Confidence Interval) | Standard error | P value | Partial R ² | Adjusted R ² |
|--------------------------|---|----------------|------------------|------------------------|-------------------------|
| Age group | | | | | 0.021 |
| <49 | <i>reference value</i> | | | | |
| 50-59 | 0.17 (-0.058 to 0.39) | 0.11 | 0.15 | 0.0023 | |
| 60+ | -0.089 (-0.34 to 0.16) | 0.13 | 0.48 | 0.00055 | |
| Continent | | | | | |
| North America | <i>reference value</i> | | | | |
| Europe | -0.20 (-0.44 to 0.034) | 0.12 | 0.094 | 0.0031 | |
| Other | 0.093 (-0.23 to 0.42) | 0.17 | 0.58 | 0.00034 | |
| Diagnosis | | | | | |
| Dupuytren's contracture | <i>reference value</i> | | | | |
| Adhesive capsulitis | 0.096 (-0.14 to 0.33) | 0.12 | 0.43 | 0.00070 | |
| Kienböck's disease | 0.49 (0.23 to 0.75) | 0.13 | <0.001 | 0.015 | |
| Other | 0.049 (-0.45 to 0.55) | 0.26 | 0.85 | 0.000040 | |
| Surgeon variables | | | | | |
| Years in practice | | | | | 0.12 |
| 0-5 | <i>reference value</i> | | | | |
| 6-10 | -0.16 (-0.60 to 0.29) | 0.23 | 0.492 | 0.0029 | |
| 11-20 | -0.37 (-0.77 to 0.028) | 0.20 | 0.068 | 0.020 | |
| 21-30 | -0.70 (-1.2 to -0.22) | 0.25 | 0.005 | 0.047 | |
| Subspecialty | | | | | |
| Hand and wrist | <i>reference value</i> | | | | |
| Other | -0.71 (-1.1 to -0.36) | 0.18 | <0.001 | 0.089 | |

Bold indicates statistical significance, $P < 0.05$.

unwillingness of patients to participate in our survey. On the contrary, we received an abundance of positive reactions to our announcement that we were asking patients about their research interests, and a great number of patients responded to the survey. However, some moderators of patient support groups tried to charge us for the distribution of our survey, others indicated that they were of the opinion that group members would not appreciate doctors having access to the group, and in some groups, members posted so frequently that the link to our survey easily got lost in the vast number of daily posts. With the permission of the moderators, we reposted the invitation several times, which was successful for some diagnosis groups. In spite of our difficulties to have patients fill out the survey, responses of the surgeons may still be useful for researchers searching for inspiration for new research questions that are valuable to field experts. Second, classification of the comments into categories is somewhat arbitrary and may be performed with various levels of specificity. If a higher level of specificity is used, differences between surgeons and patients might be identified. Third, we cannot rule out that patients completed the questionnaire more than once from different IP-addresses.

We found that - in broad categories - patient research priorities did not differ substantially from surgeon priorities, although some differences could be identified on a more detailed level of classification. For painful upper extremity conditions, patients were most concerned with achieving alleviation of pain, while surgeons tended to be more interested in specific surgical techniques and different nonsurgical treatment methods. Surgeons showed more interest in the natural course of disease, while patients were more interested in etiology.

We found that patients were significantly more interested in patient participation in research than surgeons. Surgeons think that patients may not be interested in scientific research, or that they do not

have sufficient medical knowledge to assist with study development. To the contrary, we found that patients are quite interested in helping to establish research priorities and determining relevant outcome measures. Prior studies found that collaborations between patients and researchers can be an effective method to broaden the research agenda and to identify outcomes that are important to patients. Patients are the experts about what matters to them, and this is becoming increasingly important as we are moving towards value-based healthcare. Surgeons with the most experience were less interested than the rest of the surgeons involving patients in developing research. This finding may support the notion that younger generations of doctors are more open to efforts that make scientific research more patient-centered and accessible.

Our cross-sectional survey among a large international group of patients and orthopedic surgeons showed that patients and surgeons typically have similar research interests, and that addressing patients through social media is useful to broaden the research scope and may help design studies that are important to patients. It could be useful to create an online platform to connect interested patients with researchers that distributes surveys to guide future musculoskeletal studies. Our current study may facilitate the movement towards scientific research that is understandable, important, and accessible to patients.

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