

2015

Patient expectations and long-term outcomes in rheumatoid arthritis patients: results from the SARA (Silicone Arthroplasty in Rheumatoid Arthritis) study

K. C. Chung

K. W. Nellans

Hofstra Northwell School of Medicine

P. B. Burns

E. F. S. Wilgis

F. D. Burke

*See next page for additional authors*Follow this and additional works at: <https://academicworks.medicine.hofstra.edu/articles> Part of the [Orthopedics Commons](#)

Recommended Citation

Chung K, Nellans K, Burns P, Wilgis E, Burke F, Fox D, Kim H. Patient expectations and long-term outcomes in rheumatoid arthritis patients: results from the SARA (Silicone Arthroplasty in Rheumatoid Arthritis) study. . 2015 Jan 01; 34(4):Article 265 [p.]. Available from: <https://academicworks.medicine.hofstra.edu/articles/265>. Free full text article.

This Article is brought to you for free and open access by Donald and Barbara Zucker School of Medicine Academic Works. It has been accepted for inclusion in Journal Articles by an authorized administrator of Donald and Barbara Zucker School of Medicine Academic Works.

Authors

K. C. Chung, K. W. Nellans, P. B. Burns, E. F. S. Wilgis, F. D. Burke, D. A. Fox, and H. M. Kim



HHS Public Access

Author manuscript

Clin Rheumatol. Author manuscript; available in PMC 2015 April 01.

Published in final edited form as:

Clin Rheumatol. 2015 April ; 34(4): 641–651. doi:10.1007/s10067-014-2775-z.

Patient expectations and long-term outcomes in rheumatoid arthritis patients: results from the SARA (Silicone Arthroplasty in Rheumatoid Arthritis) study

Kevin C. Chung,

Department of Surgery, Section of Plastic Surgery, University of Michigan Health System, Ann Arbor, MI, USA

Kate W. Nellans,

Hofstra North Shore Long Island Jewish School of Medicine, Manhasset, NY, USA

Patricia B. Burns,

Department of Surgery, Section of Plastic Surgery, University of Michigan Health System, Ann Arbor, MI, USA

E. F. Shaw Wilgis,

Curtis National Hand Center, Baltimore, MD, USA

Frank D. Burke,

Pulvertaft Hand Centre, Derby, UK

David A. Fox, and

Department of Internal Medicine, Division of Rheumatology, University of Michigan Health System, Ann Arbor, MI, USA

H. Myra Kim

Center for Statistical Consultation and Research, University of Michigan, 3550 Rackham, 915 E. Washington Street, Ann Arbor, MI 48109-1070, USA

H. Myra Kim: myrakim@umich.edu

Abstract

Little evidence exists to understand the influence of patient expectations on outcomes for silicone metacarpophalangeal arthroplasty (SMPA). The purpose of this paper is to compare long-term treatment outcome experiences regarding hand function/appearance for a surgical and nonsurgical cohort of rheumatoid arthritis (RA) patients and contrast them to expectations at baseline. This sample is part of a larger multicenter prospective cohort study of RA patients enrolled from 2004 to 2008. A total of 169 RA patients with severe deformities at the metacarpophalangeal (MCP) joints were recruited in the original study. Expectations for SMPA were collected at enrollment. A follow-up patient-reported questionnaire was completed at long-term follow-up. Baseline

© International League of Associations for Rheumatology (ILAR) 2014

Correspondence to: H. Myra Kim, myrakim@umich.edu.

The study is registered at ClinicalTrials.gov, NCT00124254, <http://www.clinicaltrials.gov>

Conflict of interest The authors have no financial disclosures or conflicts of interest.

expectation questionnaires were collected from 137 patients, and follow-up data from 84 patients (average 6.7 years followup). At baseline, a significantly higher percent of patients who chose surgery expected to do “Anything I want” or “More activities than I do now” 1 year from enrollment than those who chose nonsurgical treatment. At follow-up, surgical patients remained more likely to indicate that they were currently able to do “Anything” or “More activities” than nonsurgical patients. A higher percentage of surgical patients were “very satisfied” or “quite satisfied” with their treatment compared to nonsurgical patients. RA subjects who chose SMPA reported greater expectations for surgery prior to surgery and also greater levels of hand function and satisfaction at long-term follow-up.

Keywords

Patient expectations; Rheumatoid arthritis; Silicone metacarpophalangeal arthroplasty

Over the last two decades, there has been an increased interest in studying patient expectations for surgical and medical procedures. Patient expectations have become an integral part of patient-reported outcomes when comparing the effectiveness of treatments. In fact, the results from an earlier study of total hip arthroplasty patients suggested that expectations may be a better way to assess outcomes rather than the success of the treatment [1]. The study found that 86 % of patients reported their treatment was successful but only 55 % reported that their expectations were fulfilled. Understanding patient expectations can help physicians facilitate patients deriving realistic expectations that can ultimately result in greater satisfaction.

Among arthritis patients, there have been several expectation studies for total knee (TKA) and hip arthroplasty (THA) [1–13]. Results from these studies have found that expectations and satisfaction were strongly correlated [2, 4] and patients were overly optimistic in their expectations [3, 12] and that patients with greater expectations had better outcomes [4, 8, 13]. Although results varied by study, the majority of patients reported that their expectations were fulfilled after surgery [3, 7]. In contrast, a systematic review of patient expectations for TKA and THA found no consistent association between expectations, and satisfaction and treatment outcomes [6]. The disparity in these results demonstrates the difficulty in measuring patient expectations but also the importance of expectations in improving patient outcomes.

In rheumatoid arthritis (RA) patients, the hands and the metacarpophalangeal (MCP) joints, in particular, are most often affected. Silicone metacarpophalangeal arthroplasty (SMPA) has been used for over 40 years to correct both the position and functional arc of motion of the fingers. Patient expectations for SMPA have not been studied with the exception of an early look at our cohort that explored how expectations affect decision making for SMPA [14]. The study found that there was a difference in baseline expectations between those who chose surgery and those who declined surgery. Patients who planned to have surgery expected they would be able to do more activities and work and have less pain and improved appearance compared to patients not choosing surgery.

We are aware of no reports comparing pre-operative expectations for SMPA surgery to satisfaction and long-term outcomes. This paper includes a sample of RA patients from the NIH-funded SARA (Silicone Arthroplasty in Rheumatoid Arthritis) study that is in its second 5-year funding cycle. RA patients with severe deformities at the MCP joint who elected to have SMPA were compared to a nonsurgical group with a comparable level of deformity. All patients, regardless of whether they chose surgery or not, were asked about their expectations for surgery at enrollment and at minimum follow-up time of 3 years after enrollment either in the nonsurgical or in the surgical group. The purpose of this paper is to compare baseline expectations for both surgical and nonsurgical patients with regard to satisfaction and other patient-reported outcomes at long-term follow-up.

Materials and methods

Study sample

Patients were recruited as a part of a larger NIH-funded study evaluating the outcome of SMPA. RA patients were referred by their rheumatologist to one of three study centers for consideration of SMPA for severe hand deformities. All study centers received institutional review board (IRB) approval prior to the start of the study. These centers were selected because of the close working relationship between the hand surgeons and the rheumatologists at each institution. Additionally, the three sites provided a racially and socioeconomically diverse group of patients for the study [15]. Three surgeons (one at each site) were involved in the study. All surgeons were experienced with an average of 30 years of experience in treating the rheumatoid hand and followed a standard protocol to ensure consistency in technique. The larger aim of the study was to better understand and measure the global functioning of patients treated surgically versus those treated with medical management alone. The inclusion criteria required a diagnosis with RA by a rheumatologist, age 18–80 years, and severe deformity at the MCP joints. Severe deformity was determined by summing the average ulnar drift and extensor lag for each finger. Patients with a sum greater than 50° were eligible for participation in this study. Exclusion criteria included severe medical conditions preventing safe elective surgery, existing extensor tendon rupture, swan-neck or boutonniere deformities requiring surgical correction, prior MCP arthroplasty on the study hand, or the addition of disease-modifying antirheumatic drugs (DMARDs) within 3 months of enrollment. Patients requiring surgical procedures for the thumb and wrist that required a staged approach such as extensor tendon ruptures were excluded.

Study design

A prospective cohort design was used. All subjects signed informed consent forms before enrollment in the study. Patients were able to choose to either have surgery or not have surgery. We found through pilot testing that many patients had strong treatment preferences and would not consent to randomization. If the patient chose surgery, they were allowed to pick which hand they wanted to address first. Likewise, the nonsurgical group could determine which hand they preferred to be the “study hand.” Patients could elect to have surgery on the opposite hand a minimum of 1 year after the study hand. A total of 10 patients elected to have surgery on the opposite hand. During the office visit, all patients met

with a hand surgeon to discuss surgical options, but the details of the study were communicated by the study coordinator before the informed consent form was signed.

Outcome measures

Baseline expectation questionnaire—After meeting with a surgeon and discussing the surgical procedure and rehabilitation, the expectation questionnaire was administered by a research coordinator. All patients were asked to complete the baseline expectation questionnaire as if they were going to undergo SMPA. The decision to undergo surgery was not entirely known when the baseline expectation for SMPA questionnaire was completed. For example, some patients said they were unsure and others said they planned to have surgery, but actually never had the surgery. The expectation questionnaire consisted of 15 questions addressing hopes, decision-making processes, and expectations as well as perceived risks (Appendix 1). In this paper, we focused on responses to expectations for SMPA 1 year post-operative in terms of hand activities, function, pain, and appearance. The expectation questionnaire was pilot-tested prior to its use in this study for clarity and length [14].

Follow-up treatment experience questionnaire—Patients were asked to evaluate their treatment experience a minimum of 3 years following enrollment in a follow-up questionnaire administered by a research coordinator (Appendices 2 and 3). The structured follow-up questionnaire could be completed online, by mail or telephone. It consisted of 8 questions for nonsurgical patients and 10 questions for surgical patients. The four questions of interest in this study mirrored those from the expectation questionnaire. For example, the expectation questionnaire asked “What do you expect to be able to do with your hands one year from now?” whereas the follow-up questionnaire asked “What are you currently able to do with your hands?” Additionally, surgical patients were queried about the difficulty of rehabilitation and surgical complications, whereas nonsurgical patients were asked if they would reconsider surgery if they could go back to the start of the study. Both groups were asked about the satisfaction for the treatment they received for their study hands.

Other study measurements assessed at enrollment included patient-reported outcome measures (Michigan Hand Questionnaire and the Arthritis Impact Measurement Scales 2), functional tests (grip and pinch strength and the Jebson-Taylor Test), and arc of motion measurements. Outcomes were also assessed at pre-planned follow-up assessment times for a maximum of 7 years, and the 3-year analysis of these measures is presented in a previous paper [16].

Statistical analysis

Both outcomes expected at baseline and experienced at follow-up including hand function, work activities, pain, and appearance were obtained as categorical data and were dichotomized to desirable vs. not desirable responses. Specifically, each question was based on a 5-point scale, and the responses were dichotomized to 1 or 2 (better than before surgery) vs. 3, 4, or 5 (same or worse than before surgery), except the pain question which was assessed using a 6-point scale and was dichotomized to 1, 2, or 3 (less pain than before surgery) vs. 4, 5, or 6 (same or more pain than before surgery). For all outcome variables,

percentages of patients responding with desirable outcomes were reported by assessment time (baseline vs. follow-up) and also by study groups (surgical vs. nonsurgical). Differences between surgical and nonsurgical groups in expected outcomes at baseline and in realized outcomes at follow-up were each compared with the chi-square tests. Odds ratios were calculated as a summary measure of the association between the dichotomized outcome status and whether the patient was in surgical vs. nonsurgical group. Differences between the expected outcomes at baseline versus follow-up outcomes were not statistically compared; however, the follow-up outcomes were expected to be worse than the anticipated because all anticipated outcomes were asked about 1 year from enrollment, whereas the follow-up outcomes were asked about current outcome which was at minimum 3.3 years after enrollment to the study. All data were analyzed using Stata 12.1 (College Station, TX).

Results

Of the 169 patients enrolled, 137 patients (Fig. 1) completed the initial expectation questionnaire. The baseline expectation questionnaire was introduced after the study initiated, and therefore, data were not collected from participants enrolled during the first 12 months of the study start. In 2013, participants were contacted to participate in a follow-up questionnaire mirroring the baseline expectation questionnaire, and 84 patients completed the follow-up questionnaire. Subjects were contacted at an average of 6.7 years after enrollment in the study; the mean number of years after enrollment was 6.3 years (range 3.3–8.0 years) in the surgical group and 6.9 years (range 5.1–8.8 years) in the nonsurgical group. The surgical group respondents of the follow-up questionnaire included the two nonsurgical patients from the initial group that crossed over into the surgical group after 1 year in accordance with the study protocol. These patients are included in the surgical group for the analyses of follow-up surveys. A total of 16 patients out of 84 who completed the follow-up survey did not complete a baseline survey, and therefore, the follow-up survey was done in only 68 (48 %, 24 in surgical group and 44 in nonsurgical group) of 137 patients who did the baseline survey. The demographic details of the cohort as shown in Table 1. There were no differences in age, race or income between the surgical and nonsurgical subjects. However, surgical subjects were more likely to be female and have a high school or lower education.

Table 2 shows the percent of patients with more desirable outcomes expected at baseline and the percent with more desirable outcomes realized at follow-up. In terms of activities, the majority of respondents indicated that they expected to do more activities 1 year after enrollment in the study. The percentage, however, was significantly higher in surgical patients than in nonsurgical patients. At follow-up, the percentage of patients currently experiencing desirable outcomes remained higher in surgical than in nonsurgical patients; surgical patients had a significantly higher odds of currently experiencing a desirable outcomes compared to nonsurgical patients.

All other domains showed similar results. In terms of work, pain, and appearance, a significantly higher percent of surgical than nonsurgical patients anticipated more desirable outcomes. The percentages of patients who experienced desirable outcomes at follow-up in terms of work, pain, and appearance were also significantly higher in surgical patients than

in nonsurgical patients, with significantly higher odds of experiencing desirable outcomes at follow-up in surgical patients than nonsurgical patients. Statistically significant between treatment group differences in experienced outcomes remained significant for each of the four domains even after adjusting for the number of years since enrollment, and the number of years since enrollment was not a significant predictor of any of the four outcome domains.

In terms of satisfaction, a higher percentage of surgical patients were “Very satisfied” or “Quite satisfied” with the results of their surgery (83.3 %) compared to the results of their treatment received by the nonsurgical patients (62.8 %, $p=0.05$). Among SMPA patients, having achieved a more desirable appearance was the strongest predictor of satisfaction (OR=11.0; $p=0.04$ using Fisher’s exact test). Number of years since enrollment was not a significant predictor of satisfaction (OR=1.3, $p=0.51$).

Six SMPA patients reported unfulfilled expectations over the course of their treatment. Although neither being unfulfilled nor complication was significantly associated with dissatisfaction with the results of the surgery, one of the four patients with surgical complications reported being dissatisfied, while two of the six patients with unfulfilled expectations were dissatisfied.

Discussion

RA patients who are considering elective surgery such as SMPA have specific hopes and expectations. Whether these expectations are realistic and can be met is a determining factor in patient satisfaction. The data from our prospective study of RA patients allowed us to examine if patient expectations were fulfilled and what realistic expectation physicians can provide in terms of satisfaction and other long-term self-assessed hand outcomes in comparison to before surgery. Overall, our results found that SMPA patients showed high expectations and their satisfaction at long-term follow-up was high as well. More than 85 % of SMPA patients expected better outcomes in 1 year from surgery for each of hand function, pain, work, and appearance. At more than 6 years after surgery on average, at least 60 % of the SMPA patients reported better outcomes than before surgery for function, pain, and appearance. In addition, only 20 % of SMPA patients expressed having any expectations that were not fulfilled, and 83 % were quite or very satisfied with the results of their surgery.

One theoretical model for expectations is that patients with greater expectations report better outcomes [17, 18]. According to this model, patients who expect SMPA will enhance their ability to use their hands will report improved hand function after surgery. Additionally, a recent systematic review of patient expectations and patient-reported outcomes after surgery showed that 47 % (28 of 60 articles) found a correlation between positive expectations and improved outcomes [19]. Mancuso et al. found that THA patients with higher expectations had greater satisfaction [2]. Our results did not confirm this model for surgical subjects. Our data, however, included only 24 SMPA patients with both baseline expectation and follow-up outcome data, and most of them expressed high expectation for SMPA (i.e., most expected SMPA will enhance their ability, reduce pain, or improve appearance 1 year after

surgery) making it impossible to assess variability in follow-up outcomes from baseline expectation.

We also found that pre-operative expectations for the surgical group may have been unrealistic. As seen in Fig. 2, the actual outcomes reported at follow-up for the surgical group are lower than anticipated at enrollment. The difference between expectations and realized outcomes is greater for hand function and work and less for pain and appearance. As seen in previous arthroplasty studies, patients tended to be overoptimistic about the outcome of surgery [3, 12]. However, we also note that the follow-up outcomes were obtained on average more than 6 years after the surgery, while expectation for SMPA at enrollment was obtained while considering 1 year from enrollment. Mannion et al. found that patients undergoing TKA underestimated the time to recover and overestimated the gains in pain and function [3]. Nilsson et al. found that TKA patients' expectations were realistic about pain but not for physical activities [12].

Although the difference was only marginally significant, in our cohort, greater percent of surgical subjects reported satisfaction with treatment than nonsurgical subjects. It had been hypothesized that aesthetic improvements as a result of SMPA were the most important factor in determining satisfaction [20]. Our results were consistent with this. Of all post-surgical outcomes we assessed in this study, having achieved more desirable aesthetic outcomes than before surgery was the most important predictor of satisfaction with the results of the surgery. Our own recent study also showed that satisfaction of patients having undergone SMPA was closely correlated to improvements in the MCP arc of motion and position of the fingers, establishing the relationship between patient satisfaction and objective measures, although they did not find correlation to improved grip or pinch strength [21].

This study has several limitations. We began collecting expectation data a year after the start of the study. This meant that we were not able to survey expected outcomes at enrollment in those patients enrolled early into the study although we were able to assess their follow-up outcomes. This resulted in a relatively small number of surgically treated patients where both baseline and follow-up data were collected, which is one reason for not being able to evaluate whether higher expectation prior to surgery was positively correlated with better outcome or higher satisfaction. Also, in collecting the follow-up outcomes from 3 to 7 years after enrollment, we lost data from subjects who died, withdrew, and were loss to follow-up. The lack of complete data is a source of sampling bias and limits our ability to make comparisons and draw conclusions from the data. Another limitation is the difference in mode of administration for the expectation and follow-up questionnaires. The expectation questionnaires were completed in person at the clinic whereas the follow-up questionnaires were completed by mail, online, or over the telephone. However, due to the long distance many patients travel to return to the clinic, we felt our response rate would be higher via telephone or online. Finally, the expectation and outcome questionnaires were designed for the study and are not validated instruments, although the outcome questionnaire does have face validity based on the construct of expectation domains. In addition, our findings of significant differences in expectations for SMPA between patients who chose versus did not choose SMPA provides validity for the expectation questionnaire. Furthermore, the follow-

up questionnaire was designed to mirror the questions asked in the initial expectation questionnaire.

The results from this study are unique because both surgical and nonsurgical patients were asked their expectations at enrollment and outcomes after extended follow-up. Our results showing unfulfilled or potentially overly optimistic expectations highlight the need for rheumatologists and surgeons to continue in their efforts to provide realistic expectations for SMPA. The use of education aids may help patients understand the full effect of surgical treatments for the RA hand. Our results from patient-assessed expectations and long-term outcomes can also guide surgeons and rheumatologists in providing appropriate counseling to patients making treatment decisions.

Acknowledgments

Research reported in this publication was supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases of the National Institutes of Health under Award Number (2R01 AR047328-06) and a Midcareer Investigator Award in Patient-Oriented Research (2K24 AR053120-06) (to Dr. Kevin C. Chung). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The authors acknowledge the assistance of Evan McGlenn (University of Michigan) in converting the survey into a web-based format. We also appreciate the ongoing efforts of Lorraine Zellers (Curtis National Hand Center) and Melanie Arundell (Pulvertaft Hand Centre) to facilitate long-term followup of the cohort.

Appendix 1. Expectations with MCP arthroplasty questionnaire

1. Have you decided to have knuckle replacement surgery?
 YES NO UNDECIDED

2. What do you hope knuckle replacement surgery will do for you?

Please list all your hopes in the left hand column of the table below.
 (If you are not having surgery, please list what you would hope for if you ever chose to have the operation).

Then circle how important each hope is to you.

WHAT DO YOU HOPE KNUCKLE REPLACEMENT SURGERY WILL DO FOR YOU?	Very Important	Somewhat Important	Not Very Important	Not at All Important

3. How important are each of the following to you when deciding whether or not to have knuckle replacement surgery? Please circle one answer for each:

	Very Important	Somewhat Important	Not Very Important	Not at All Important
a. Hand weakness				
b. Being able to do everyday activities (hold a glass of water; turn a key in a lock)				
c. Being able to do your normal work (including your job, housework or schoolwork)				
d. Hand pain				
e. Hand appearance				
f. Other _____				

4. What do you expect to be able to do with your hands one year from now? Please circle one:

a. Anything I want
b. More activities than I do now
c. The same kinds of activities I do now
d. A little less than I can do now
e. A lot less than I can do now

5. What do you expect to be able to do in terms of your work (including job, housework and schoolwork) one year from now? Please circle one:

a. Everything I need to do
b. More than I can do now
c. The same amount of work I do now
d. A little less than I can do now
e. A lot less than I can do now

6. How much pain related to your knuckles do you expect to have one year from now? Please circle one:

a. No pain
b. Much less pain than I have now
c. A little less pain than I have now
d. The same amount of pain I have now
e. A little more pain than I have now
f. A lot more pain than I have now

7. What do you expect your hands to look like one year from now? Please circle one:

a. Almost perfect
b. Much better than they do now
c. The same as they do now
d. A little worse than they do now
e. A lot worse than they do now

8. What bothers you most about how rheumatoid arthritis has affected your knuckles?
Please circle one:

a. Pain
b. The appearance of my hands
c. Weakness in my hands
d. I can't do things I would like to do with my hands
e. I can't do my work properly (job,housework or schoolwork)
f. Other _____

9. Whose opinion was most important to you when deciding whether or not to have knuckle replacement surgery? Please circle one:

a. Hand surgeon
b. Rheumatologist
c. Primary care doctor/family doctor/general practitioner
d. Spouse/partner
e. Other family member.
f. Self
g. Friends
h. Other health care professional _____
i. People who have had this kind of surgery before

10. Have you ever discussed knuckle replacement surgery with your Primary Care Doctor/Family Doctor/General Practitioner?
YES NO

11. Do you know anyone who has had knuckle replacement surgery for rheumatoid arthritis?
YES NO

If yes, how satisfied was that person with their surgery? Please circle one:

Very Satisfied	Quite Satisfied	Somewhat Satisfied	Not Very Satisfied	Not at All Satisfied
1	2	3	4	5

12. How difficult do you think rehabilitation following knuckle replacement surgery will be? (Please give us your opinion even if you are not having surgery) Please circle one:

a. Not difficult at all
b. A little difficult
c. Somewhat difficult
d. Difficult
e. Very difficult

13. How likely do you think it is that there would be any serious complications, (such as infection or excess bleeding in your knuckles), after surgery? (Please give us your opinion even if you are not having surgery) Please circle one:

a. 0 % chance of serious complications
b. Less than 5 % chance of serious complications
c. 5-10% chance of serious complications
d. 10-20% chance of serious complications
e. Greater than 20% chance of serious complications

14. Have you had knuckle replacement surgery before? YES NO

15. Have you ever had any other joints replaced? YES NO
If yes, which joints? _____

Appendix 2. Surgical subject follow-up questionnaire

1. What are you currently able to do with your hands?
 - a. Anything I want
 - b. More activities than I could do before surgery
 - c. The same kinds of activities I did before surgery

- d. A little less than I could do before surgery
 - e. A lot less than I could do before surgery
- 2. What are you currently able to do in terms of your work? (including job, housework, and schoolwork)
 - a. Everything I need to do
 - b. More than I could do before surgery
 - c. The same amount of work I could do before surgery
 - d. A little less than I could do before surgery
 - e. A lot less than I could do before surgery
- 3. How much pain related to your knuckles do you have currently?
 - a. No pain
 - b. Much less pain than I had before surgery
 - c. A little less pain than I had before surgery
 - d. The same amount of pain that I had before surgery
 - e. A little more pain than I had before surgery
 - f. A lot more pain than I had before surgery
- 4. How would you describe the current appearance of your hands?
 - a. Almost perfect
 - b. Much better than before surgery
 - c. The same as before surgery
 - d. A little worse than before surgery
 - e. A lot worse than before surgery
- 5. How satisfied are you with the results of your surgery?
 - a. Very satisfied
 - b. Quite satisfied
 - c. Somewhat satisfied
 - d. Not very satisfied
 - e. Not at all satisfied
- 6. How difficult was your rehabilitation following knuckle replacement surgery?
 - a. Not difficult at all
 - b. A little difficult
 - c. Somewhat difficult

- d. Difficult
 - e. Very difficult
7. Did you have any expectations, which were not fulfilled regarding your surgery? If so, what were they?
- a. Yes (please explain)_____
 - b. No
8. Please indicate any complications that you had regarding your knuckle joint replacement surgery
- a. Implant fracture
 - b. Implant dislocation
 - c. Infection
 - d. Needed additional surgery
 - e. Other (please specify)_____
9. Do you feel that your fingers have drifted after the surgery?
- a. Yes
 - b. No
10. Have you had any additional surgeries on your hands after your knuckle joint replacement surgery? If so, what procedures have you had?
- a. Yes (please explain)_____
 - b. No

Appendix 3. Nonsurgical subject follow-up questionnaire

1. What are you currently able to do with your hands?
- a. Anything I want
 - b. More activities than I could do before I enrolled in the study
 - c. The same kinds of activities that I did before I enrolled in the study
 - d. A little less than I could do before I enrolled in the study
 - e. A lot less than I could do before I enrolled in the study
2. What are you currently able to do in terms of your work? (including job, housework, and schoolwork)
- a. Everything I need to do
 - b. More than I could do before I enrolled in the study
 - c. The same amount of work I could do before I enrolled in the study

- d. A little less than I could do before I enrolled in the study
 - e. A lot less than I could do before I enrolled in the study
- 3. How much pain related to your knuckles do you have currently?
 - a. No pain
 - b. Much less pain than I had before I enrolled in the study
 - c. A little less pain than I had before I enrolled in the study
 - d. The same amount of pain that I had before I enrolled in the study
 - e. A little more pain than I had before I enrolled in the study
 - f. A lot more pain than I had before I enrolled in the study
- 4. How would you describe the appearance of your hands?
 - a. Almost perfect
 - b. Much better than before I enrolled in the study
 - c. The same as before I enrolled in the study
 - d. A little worse than before I enrolled in the study
 - e. A lot worse than before I enrolled in the study
- 5. Do you feel that your fingers have drifted since you first enrolled in the RA study?
 - a. Yes
 - b. No
- 6. How satisfied are you with the treatment you have received for your hands?
 - a. Very satisfied
 - b. Quite satisfied
 - c. Somewhat satisfied
 - d. Not very satisfied
 - e. Not at all satisfied
- 7. If you could go back in time to the beginning of the study, would you decide to undergo surgery?
 - a. Yes
 - b. No
- 8. What were your reasons for deciding to participate in this study as a non-surgical patient? (please check all that apply)
 - a. To help other patients in the future
 - b. Monetary reimbursement

- c. My doctor wanted me to be in the study
- d. Other (please specify)_____

References

1. Burton KE, Wright V, Richards J. Patients' expectations in relation to outcome of total hip replacement surgery. *Ann Rheum Dis.* 1979; 38:471–474. [PubMed: 518147]
2. Mancuso CA, Salvati EA, Johanson NA, et al. Patients' expectations and satisfaction with total hip arthroplasty. *J Arthroplasty.* 1997; 12:387–396. [PubMed: 9195314]
3. Mannion AF, Kampfen S, Munzinger U, et al. The role of patient expectations in predicting outcome after total knee arthroplasty. *Arthritis Res Ther.* 2009; 11:R139. [PubMed: 19772556]
4. Mahomed NN, Liang MH, Cook EF, et al. The importance of patient expectations in predicting functional outcomes after total joint arthroplasty. *J Rheumatol.* 2002; 29:1273–1279. [PubMed: 12064846]
5. Mancuso CA, Sculco TP, Salvati EA. Patients with poor preoperative functional status have high expectations of total hip arthroplasty. *J Arthroplasty.* 2003; 18:872–878. [PubMed: 14566742]
6. Haanstra TM, van den Berg T, Ostelo RW, et al. Systematic review: do patient expectations influence treatment outcomes in total knee and total hip arthroplasty? *Health Qual Life Outcome.* 2012; 10:152.
7. Mancuso CA, Jout J, Salvati EA, et al. Fulfillment of patients' expectations for total hip arthroplasty. *J Bone Joint Surg Am.* 2009; 91:2073–2078. [PubMed: 19723982]
8. Gandhi R, Davey JR, Mahomed N. Patient expectations predict greater pain relief with joint arthroplasty. *J Arthroplasty.* 2009; 24:716–721. [PubMed: 18701241]
9. Haworth RJ, Hopkins J, Ells P, et al. Expectations and outcome of total hip replacement. *Rheumatol Rehabil.* 1981; 20:65–70. [PubMed: 7280482]
10. Judge A, Cooper C, Arden NK, et al. Pre-operative expectation predicts 12-month post-operative outcome among patients undergoing primary total hip replacement in European orthopaedic centres. *Osteoarthritis Cartil.* 2011; 19:659–667. [PubMed: 21447395]
11. Lingard EA, Sledge CB, Learmonth ID. Patient expectations regarding total knee arthroplasty: differences among the United States, United Kingdom, and Australia. *J Bone Joint Surg Am.* 2006; 88:1201–1207. [PubMed: 16757751]
12. Nilsson AK, Toksvig-Larsen S, Roos EM. Knee arthroplasty: are patients' expectations fulfilled? A prospective study of pain and function in 102 patients with 5-year follow-up. *Acta Orthop.* 2009; 80:55–61. [PubMed: 19234886]
13. Becker R, Doring C, Denecke A, et al. Expectation, satisfaction and clinical outcome of patients after total knee arthroplasty. *Knee Surg Sports Traumatol Arthrosc.* 2011; 19:1433–1441. [PubMed: 21811857]
14. Mandl LA, Burke FD, Shaw Wilgis EF, et al. Could preoperative preferences and expectations influence surgical decision making? Rheumatoid arthritis patients contemplating metacarpophalangeal joint arthroplasty. *Plast Reconstr Surg.* 2008; 121:175–180. [PubMed: 18176218]
15. Chung KC, Kotsis SV, Fox DA, Regan M, Burke FD, Wilgis EFS, Kim HM. Differences between the United States and the United Kingdom in the treatment of deforming rheumatoid arthritis: analyses from a hand arthroplasty trial. *J Clin Rheum.* 2010; 29:363–367.
16. Chung KC, Burns PB, Kim HM, et al. Long term followup for rheumatoid arthritis patients in a multicenter outcomes study of silicone metacarpophalangeal joint arthroplasty. *Arthritis Care Res.* 2012; 64:1292–1300.
17. Flood AB, Lorence DP, Ding J, et al. The role of expectations in patients' reports of post-operative outcomes and improvement following therapy. *Med Care.* 1993; 31:1043–1056. [PubMed: 7694013]
18. Koyama T, McHaffie JG, Laurienti PJ, et al. The subjective experience of pain: where expectations become reality. *Proc Natl Acad Sci U S A.* 2005; 102:12950–12955. [PubMed: 16150703]

19. Waljee JF, McGlenn EP, Davis Sears E, et al. Patient expectations and patient-reported outcomes in surgery: a systematic review. *Surgery*. 2014
20. Mandl LA, Galvin DH, Bosch JP, et al. Metacarpophalangeal arthroplasty in rheumatoid arthritis: what determines satisfaction with surgery? *J Rheumatol*. 2002; 29:2488–2491. [PubMed: 12465140]
21. Waljee JF, Chung KC. Objective functional outcomes and patient satisfaction after silicone metacarpophalangeal arthroplasty for rheumatoid arthritis. *J Hand Surg*. 2012; 37:47–54.

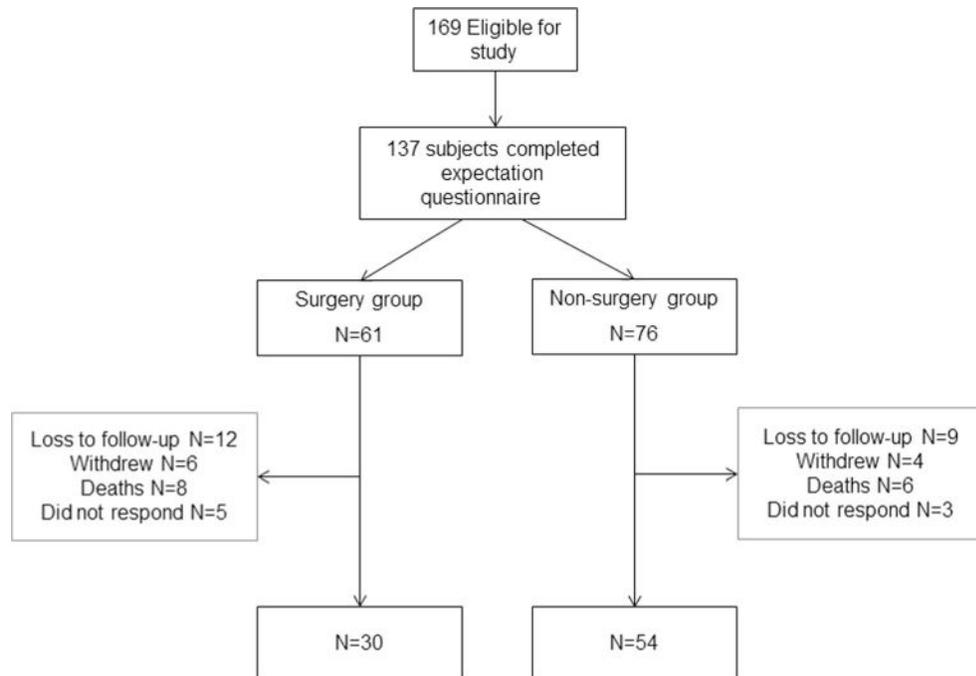


Fig. 1.
Study flow chart

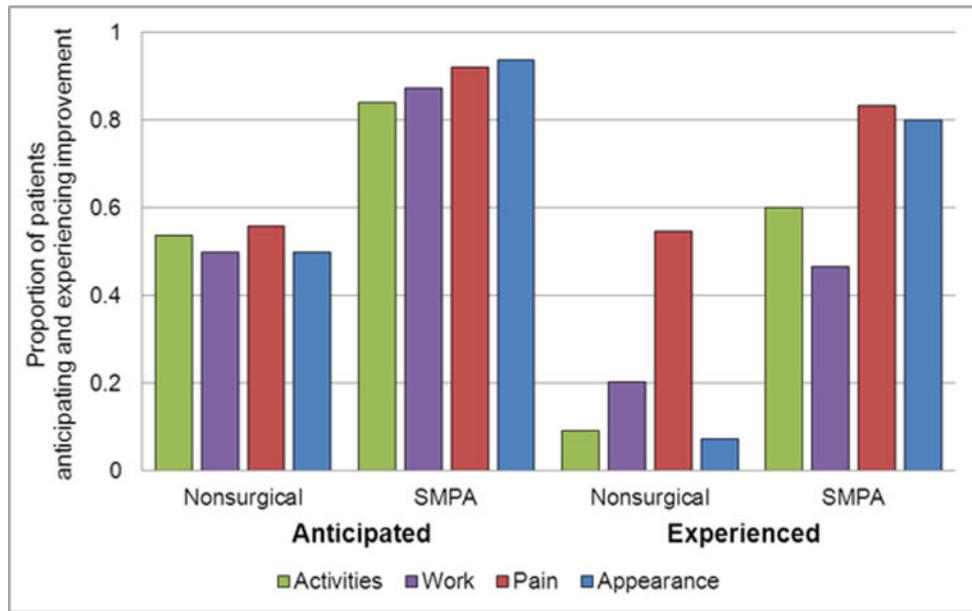


Fig. 2. Anticipated outcomes compared to experienced outcomes in Surgical (*SMPA*) and Nonsurgical Patients with Severe RA Hand Deformities

Table 1

Comparison of demographic values for surgical vs. nonsurgical subjects

Demographic variables	Surgical (N=61)	Nonsurgical (N=76)	<i>p</i> value
Age, mean (SD)	60 (8)	61 (11)	0.48
Female, no. (%)	50 (82)	50 (66)	0.03
Race, White, no. (%) ^a	50 (91)	66 (89)	0.74
Education, high school degree, no. (%) ^a	34 (60)	30 (41)	0.03
Income, <\$50,000, no. (%) ^a	42 (76)	46 (66)	0.19

^aEight participants are missing race, 6 are missing education data, and 12 are missing income data

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2

Percent of patients with more desirable outcome expected at baseline and realized at follow-up for all patients and by treatment group

Domain	Total (%)	By group		p value ^c	OR (95 % CI)	
		Surgical (%)	Nonsurgical (%)			
Activities	Anticipated ^a	67 (91/136)	85 (50/59)	53 (41/77)	<0.001	4.9 (2.0, 12.8)
	Experienced ^b	27 (23/84)	60 (18/30)	9 (5/54)	<0.001	14.7 (4.5, 47.6)
Work	Anticipated	66 (90/136)	88 (52/59)	49 (38/77)	<0.001	7.6 (2.9, 22.1)
	Experienced	30 (25/84)	47 (14/30)	20 (11/54)	0.01	3.4 (1.3, 9.1)
Pain	Anticipated	73 (98/135)	93 (55/59)	57 (43/76)	<0.001	10.6 (3.3, 43.4)
	Experienced	65 (54/83)	83 (25/30)	55 (29/53)	0.009	4.1 (1.4, 12.5)
Appearance	Anticipated	69 (94/136)	93 (55/59)	51 (39/77)	<0.001	13.4 (4.2, 54.9)
	Experienced	33 (28/84)	80 (24/30)	7 (4/54)	<0.001	50.0 (12.9, 193.9)

Both baseline hand outcome expectation and follow-up responses are dichotomized to more desirable outcomes versus not corresponding to scores of 1 or 2 vs. 3, 4, or 5. For example, for activity domain, anything I want/need to do or more activities than I could do (1 or 2) vs. less desirable outcomes (3, 4, or 5)

^a Outcomes anticipated from baseline expectation questionnaire

^b Outcomes experienced from follow-up questionnaire

^c From comparison between surgical vs. nonsurgical group