

# Barriers to Reconstructive Hand Surgery for Rheumatoid Arthritis in China: A Multicenter Survey of Patients and Physicians

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**Background:** China has a similar rheumatoid arthritis (RA) disease burden compared with other countries, yet RA patients rarely receive surgical treatment for hand deformities that limit function and impact appearance. We investigated potential barriers to rheumatoid hand surgery in China.

**Methods:** Patients with RA, rheumatologists, and hand surgeons at 3 large tertiary hospitals in Beijing completed questionnaires that assess knowledge and attitudes surrounding RA hand surgery. We calculated descriptive statistics and compared responses among groups using chi-square and Fisher exact tests as appropriate.

**Results:** One hundred RA patients with hand deformities and 94 physicians completed the surveys. No patients had received hand surgery, and just 13% were aware of this treatment option. Patients and physicians most frequently cited uncertain effectiveness of surgery, high cost, and risk of surgical complications as potential barriers to hand reconstruction. Rheumatologists reported low rates of referral to hand surgeons (39% referred <5% of the time and 31% never referred). Most hand surgeons (69%) had not performed metacarpophalangeal arthroplasty, a common procedure for RA hand deformities, within the past year. Some had never performed this operation.

**Conclusions:** This survey revealed multiple barriers that support previous observations of infrequent reconstruction of RA hand deformities in China. These obstacles can be addressed through patient education, coordination between specialists, and more robust hand surgeon training in common RA procedures through the application of international plastic surgery collaborations. (*Plast Reconstr Surg Glob Open* 2016;4:e1126; doi: 10.1097/GOX.0000000000001126; Published online 23 November 2016.)

**R**heumatoid arthritis (RA) affects 3.9 to 6.3 million people in China, with the highest prevalence found in urban areas.<sup>1–3</sup> Over 70% of patients with RA develop hand dysfunction, including joint deformities that are both disfiguring and disabling.<sup>4</sup> Although disease progression is managed increasingly well by new generations of antirheumatic drugs, once joint deformities occur, they can only be corrected using surgical procedures such as

arthroplasty, arthrodesis, and tenosynovectomy.<sup>5</sup> Despite evidence supporting the use of these operations, RA patients in China have hand surgery at a much lower rate compared to their counterparts in the United States, Western Europe, and Japan.<sup>6</sup> The factors preventing Chinese RA patients from accessing surgical treatments that could offer better hand function, appearance, and quality of life have not been investigated. Recent healthcare reforms in China and its aging population may foster greater access to and interest in hand surgery.<sup>7–9</sup> Early identification of

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barriers faced by patients will help clinicians, policy makers, and international partners create solutions that enable patients to obtain reconstruction.

Patient, physician, and health system factors can all influence the accessibility and utilization of medical services. Among Medicare beneficiaries in the United States, for example, higher socioeconomic status and younger age were associated with increased rates of rheumatoid hand surgery.<sup>10</sup> In Hong Kong, a study of osteoarthritis patients found a lack of knowledge about total joint replacement and revealed that misconceptions often dissuaded those who were aware from pursuing surgery.<sup>11</sup> Physician attitudes, training, and familiarity with evidence also impact patients' treatment decisions and provision of services. Alderman et al<sup>12,13</sup> found that rheumatologists and hand surgeons in the United States disagree about the optimal timing and the efficacy of rheumatoid hand surgery, which could impede collaborative care and referral. The structure of the Chinese healthcare system may also influence patients' utilization of services. It differs from that of the United States in 3 key ways. First, primary care is not a universal practice in China. Most patients do not have regular appointments for health maintenance and preventive care. Instead, they visit specialists at tertiary hospitals often without referral.<sup>2</sup> Second, many hospitals do not have scheduled appointments. Patients queue in the morning to register to see a specific clinician later that day. Due to high patient volumes, some patients must repeat this process for multiple days to be seen.<sup>14,15</sup> Third, many Chinese health centers are highly specialized (eg, an orthopedic surgery hospital or a breast cancer hospital) rather than general hospitals, which means that interdisciplinary coordination must occur between institutions. Compared with the United States where primary care physicians directly refer patients to the appropriate specialists, patients in China often navigate among discrete specialty centers on their own without a referral or scheduled visit.

Recent evolutions in Chinese social and healthcare structure, including the 2009 healthcare reforms, the aging population and changing patterns of elder care will likely enable and motivate more RA patients to seek out reconstruction. Before 2009, 88% of Chinese had health insurance, and the average reimbursement for medical services (eg, inpatient care and outpatient appointments) and prescriptions was 35%. At that time, median annual direct medical costs of RA per patient-year were estimated to be 5,457 Renminbi (RMB) (\$1,546). Paying for 65% out of pocket would be difficult for many patients, 89% of whom made less than 36,006 RMB (\$10,200) per year.<sup>2</sup> As of 2011, over 95% are insured, mean reimbursement has increased to 47%, and more people are utilizing the healthcare system. The government is continuing to work toward universal coverage by 2020.<sup>8,9</sup> Reimbursement for RA services still varies widely (40%–100%) by insurance plan.<sup>2</sup> In addition to a shifting landscape of healthcare coverage, China's elderly population has increased from 7.6% in the 1980s to 14% in 2013.<sup>16,17</sup> This may lead to a larger burden of RA, which typically occurs after age 45. Patients who live with the disease for longer tend to develop more sequelae such as hand deformities. Historically, elderly

Chinese have benefited from the Confucian tradition of being cared for by younger relatives, which may have diminished their desire to seek treatment for function-limiting RA hand deformities. China's "one child policy" has undermined this type of elder care because there are fewer people in younger generations.<sup>7,16</sup> The combination of an aging population with higher RA prevalence and declining rates of elder care is likely to increase patients' desire to pursue reconstruction for hand deformities to maintain independence and physical function. With expanding access to health services, they will likely be able to do so.

China currently has a large disease burden related to RA, and recent social and health system changes have created an environment that favors increasing demand for hand reconstruction. Yet, historically, low rates of rheumatoid hand surgery and previous studies suggest that there are obstacles preventing patients from undergoing evidence-based procedures. Therefore, we performed a survey of RA patients, rheumatologists, and hand surgeons in Beijing to identify these obstacles, so that they may be addressed. We hypothesized that limited patient knowledge, low referral rates, and perceived economic barriers prevent broader utilization of hand surgery for RA.

## METHODS

Our institutional review board approved this study.

### Sample

We surveyed patients with RA, rheumatologists, and hand surgeons at 3 tertiary hospitals in Beijing (Peking Union Medical College Hospital, Peking University People's Hospital, and Jishuitan Hospital). These sites were chosen for their expertise in rheumatology and orthopedic surgery, high patient volumes, and status as destinations for patient care and teaching. Patient inclusion criteria were as follows: age over 18 years, previous diagnosis of RA, and visible hand deformities characteristic of RA (eg, ulnar deviation, joint nodules, Boutonniere deformity, and swan-neck deformity). Rheumatologists and hand surgeons who had completed residency training and currently practiced in China were eligible. This included staff physicians at our sites and visiting doctors from other provinces.

### Survey Development

Questionnaires were developed through an iterative process involving literature review, expert review, and pretesting in the case of the patient survey. We used previous studies of China's healthcare system and culture, RA, and patient and physician attitudes to create each survey.<sup>1–3,5,6,11–13,15,18–23</sup> The themes and items were then reviewed by collaborators with clinical and/or survey methodology expertise to assess content validity and were revised based on their feedback.<sup>24,25</sup> Each instrument was created in English and then (1) translated to Chinese and (2) back translated to English by 2 separate collaborators to ensure accuracy.<sup>23</sup> A third researcher compared the back translation and original English versions. The Chinese version was modified to address any inconsistencies in meaning.

The patient survey was pretested through 12 interviews with RA patients to ensure it was applicable and feasible.<sup>25</sup> After administering the survey, the interviewer asked each pretest patient to provide feedback on individual questions and the applicability of topics addressed by the instrument. The patient survey was revised based on pretest feedback, circulated among collaborators for approval, and finalized. Because the physician survey was designed for participants with similar characteristics to the research team, it was pretested through expert review by clinical collaborators from the 3 sites in Beijing.

### Data Collection

During the summer of 2015, we recruited a convenience sample of 100 patients from rheumatology clinics before or after their appointments. Patients who met our inclusion criteria and expressed interest in the study were asked to complete the questionnaire. Researchers administered the survey aloud to patients with poor visual acuity or low literacy. Rheumatologists and hand surgeons were recruited before or after their clinics or from departmental meetings. All physicians who were approached agreed to participate. We also invited rheumatologists attending a national rheumatology conference held at 1 of our sites to participate. Questionnaires were distributed during a morning conference session and collected during a scheduled break a few hours later. We offered patients and physicians free pens as an incentive for completing the surveys.

### Data Analysis

Patient and physician data were entered separately. We calculated descriptive statistics for questionnaire responses and participant characteristics. Comparisons between patient and physician perceived barriers were done using chi-square and Fisher exact tests as appropriate, and multiple logistic regression was used to assess for associations between demographic characteristics and endorsement of specific barriers (significance level,  $\alpha = 0.05$ ). All analyses were performed using SAS software (SAS version 9.4, copyright © 2002–2012 by SAS Institute Inc., Cary, N.C.).

## RESULTS

Our sample included 100 patients, 59 rheumatologists, and 35 hand surgeons. The patient response rate was 84%. None had undergone hand surgery, 85% were women, and the average time since RA diagnosis was 12.6 years. In addition to rheumatologists, most patients (71%) also saw traditional Chinese medicine doctors for RA care. Patient characteristics are presented in Table 1. Physician response rates were 100% in clinic, 100% at the departmental meeting, and 76% at the rheumatology conference. Physicians came from 19 provinces and were 40 years old on average (Table 2).

### Patient Factors

Ninety-five percent of patients were insured. Table 3 presents insurance schemes and typical reimbursement.<sup>9</sup> Only 13% of patients were aware that hand surgery is a

**Table 1. Patient Demographic and Disease Characteristics (n = 100)**

Mean age, y	54 ± 12
Female gender (%)	85
Education (%)	
None	10
Primary school or less	27
Junior or senior high school	45
Some college or Bachelor's degree	18
Household income (%)	
>100,000 RMB	19
60,000–99,999 RMB	19
20,000–59,999 RMB	30
<20,000 RMB	32
Patient-reported RA hand symptoms (%)	
Pain	95
Poor hand function	87
Hand deformity	90
Providers seen for RA in addition to rheumatologists (%)	
Traditional Chinese medicine doctor	71
Community health provider	30
Physical or occupational therapist	25
Hand surgeon	4

**Table 2. Physician Demographic Characteristics (n = 94)**

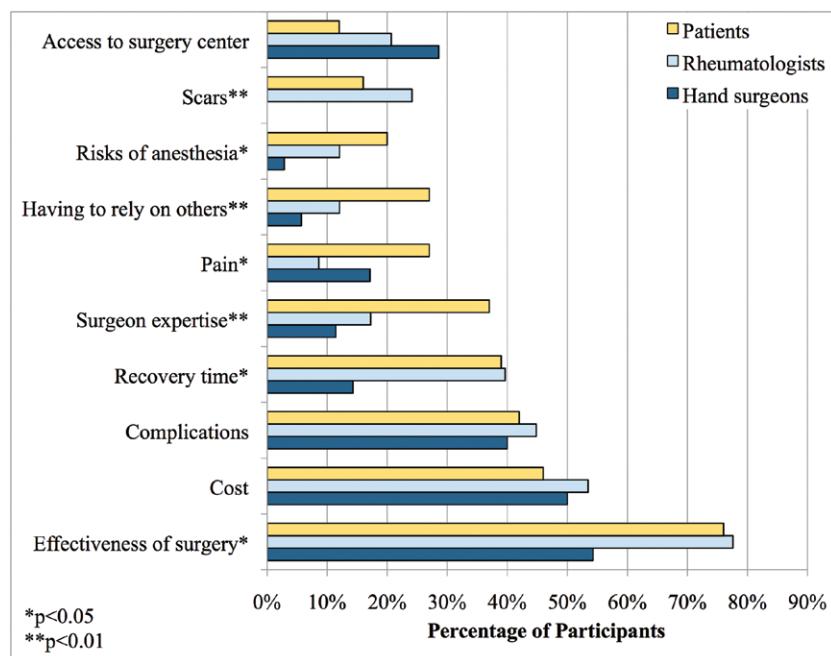
	Rheumatologists (n = 59)	Hand Surgeons (n = 35)	P
Mean age, y	38 ± 7	43 ± 10	0.01
Female gender (%)	66	14	<0.0001
Years in practice (%)			
<5	29	14	0.005
5–10	44	26	
11–20	17	20	
>20	10	37	
Practice devoted to RA (%)			
0	0	6	<0.0001
<25	7	91	
25–100	93	3	

**Table 3. Insurance Coverage and Reimbursement**

Insurance Type	Patients (n = 100)*	Typical Reimbursement <sup>9</sup>
New cooperative medical scheme (%)	52	≈40–50
Urban employee basic medical insurance (%)	38	≈60–70
Government medical insurance (%)	2	≈100
Other (ie, commercial insurance; %)	6	Varies
None (%)	5	0

\*Three patients had more than 1 type of insurance.

treatment option for RA; of this subset, 31% had learned about surgery from their rheumatologists, 46% from the Internet, and 31% from other sources, such as fellow patients. All patients were asked where they would look for information about RA hand surgery. They endorsed the following sources: rheumatologists (57%), websites (30%), hand surgeons (13%), and friends or family (12%). Four percent reported being referred to a hand surgeon for their RA, and 5% had seen a hand or orthopedic surgeon. Nearly half (48%) of patients expressed interest in having surgery now or in the future. Patients' top concerns about hand surgery were effectiveness (76%), cost (46%), and potential complications (42%; Fig. 1). Being unsure of



**Fig. 1.** Patient-reported concerns about and physician-reported barriers to rheumatoid hand surgery.

insurance reimbursement was associated with endorsing effectiveness of surgery as a concern ( $P=0.03$ ). Other associations were not significant or lacked clear directionality.

#### Physician Factors

Most rheumatologists reported referring few ( $\leq 5\%$ ) or none of their RA patients for reconstruction of hand deformities (Table 4). Overall, hand surgeons felt that they saw too few RA patients, which they attributed to few patients being referred (71%) and patient inability to afford surgery (31%). Although most (84%) were confident in their ability to safely and effectively perform RA hand surgical procedures, many surgeons had not performed metacarpophalangeal joint arthroplasty in the past year (69%) or ever (17%; Table 4). Hand surgeons were less likely than patients or rheumatologists to endorse effec-

tiveness as a potential barrier to surgery ( $P<0.05$ ). There were no significant differences in the proportion of patients and physicians reporting cost and risk of complications as concerns (Fig. 1). However, patients were more likely than rheumatologists to endorse pain, having to rely on others, and surgeon expertise as barriers ( $P<0.05$ ).

## DISCUSSION

This survey of 100 RA patients, 59 rheumatologists, and 35 hand surgeons in Beijing revealed a number of barriers contributing to the low rate of rheumatoid hand surgery observed in China. Patient factors included low awareness of hand surgery and concerns about the effectiveness, cost, and complications of surgery. Physician-related factors, including low rates of referral by rheumatologists and infrequent performance of RA procedures among hand surgeons, were also present. Lastly, we identified health system barriers, such as low insurance coverage. Through identifying these roadblocks, we hope to initiate changes that will overcome them and facilitate greater access to all evidence-based treatment modalities for RA patients in China.

The primary patient barrier was the lack of awareness of surgical reconstruction for RA hand deformities, which prevents informed decision making. Patient education is a low-cost method to address this issue and would benefit the 48% who would consider having surgery. Xu et al<sup>2</sup> report that RA patients in China attend an average of 5 physician visits each year. Each of these encounters is an opportunity to educate patients. Rheumatology appointments are particularly important because most patients surveyed preferred their rheumatologists as a source of information regarding hand surgery, likely due to their

**Table 4. Physician Attitudes, Training, and Referral Patterns**

Rheumatologist Referral Patterns (n = 59)		
Percentage of RA patients referred for hand surgery (%)		
0	31	
$\leq 5$	39	
>5	15	
Hand surgeon attitudes and training, n = 35 (%)		
Felt the number of RA patients they see is too few	86	
Felt confident in ability to safely and effectively perform RA procedures	84	
Cumulative number of MCP arthroplasties performed (%)		
0	17	
1–20	63	
21–50	14	
>50	6	
Time since most recent MCP arthroplasty operation, mo (%)		
<3	17	
3–12	12	
>12	69	

MCP = metacarpophalangeal joint.

longitudinal relationship and rapport. Communication through in-person discussion or provision of written materials (eg, pamphlets or websites) can address both treatment options and patients' concerns about surgery, such as the outcomes, costs, and risks. Written information may be more feasible for clinicians in China who have limited time with each patient. Discussion of treatment options should follow provision of information, and patients should be screened for surgical eligibility before referral.

Coordination of care between rheumatologists, who manage patients longitudinally, and surgeons who treat localized joint deformities is vital for patient outcomes.<sup>26</sup> Our survey revealed 2 physician factors that impede this process. First was the low rate of referral for hand surgery by rheumatologists, which corresponded with only 4% of patients reporting previous referral. This could reflect the difficulty of referral between discrete specialty health centers in China. A study from the United Kingdom found that the creation of a combined orthopedic-rheumatology clinic facilitated reconstructive surgery for over 50% of RA patients who failed to respond adequately to non-surgical treatments. Patients who had surgery reported improvements in pain, impairment, and activity participation, and those who did not report experienced worsening symptoms.<sup>27</sup> Creating joint clinics would be difficult in the current Chinese health system, but strengthening collaboration between rheumatologists and hand surgeons is an important target for policy makers.

Second, most hand surgeons (69%) had not performed metacarpophalangeal arthroplasty in the last year, and 17% had never performed this procedure, which is considered a mainstay of RA hand reconstruction.<sup>5,17</sup> This deficit of operative experience could be the result of seeing few RA patients, and in fact, many surgeons endorsed this. A surgeon's procedure volume correlates with patient outcomes.<sup>28</sup> As patient access to rheumatoid hand surgery improves, surgeons must be adequately trained and experienced in reconstruction to treat these patients. International collaboration between plastic surgeons is a long-standing practice to foster local expertise in developing countries. Education of local surgeons provides a more sustainable increase in access to plastic surgery services than direct operation by visiting surgeons or financial support alone.<sup>29</sup> Plastic and hand surgeons from the United States can leverage their own expertise to provide training to encourage the development of rheumatoid hand surgery in China and in turn gain international experience.

Despite China's great strides in expanding health insurance, patients and physicians in this study indicated that out-of-pocket costs and underinsurance are likely to prevent utilization of hand surgery. At least 57% of patients in this study would receive less than 50% reimbursement. This would be an impossible sum for many patients; 62% had annual household incomes of less than 60,000 RMB (equivalent to less than \$10,000). Similar economic barriers exist to obtaining medications that are a mainstay of RA treatment (eg, disease-modifying antirheumatic drugs and biologics), which can cost over \$1,000 each year.<sup>2</sup> These financial issues will take time to resolve but

will likely improve with China's economic growth and continuing steps toward universal health coverage.<sup>8,9</sup>

This study has several limitations, including potential sampling bias from recruiting patients and doctors from only the capital city of China. Beijing, however, is a destination for patients and training center for physicians from all over China, and many survey participants came from other provinces. Most physicians in this study are from the 3 tertiary hospitals in Beijing and may not be representative of the knowledge and treatment practices of rheumatologists and hand surgeons in more rural areas. Smaller and more rural health centers are likely to face greater barriers than large urban institutions. Our surveys asked participants to report on past experience, which is influenced by recall bias. Furthermore, we did not assess patients' use of newer medications, which have led to decreasing need for hand surgery in other countries. However, the cost of these drugs makes them available to few patients in China, and our focus was on the accessibility of hand surgery to those with existing deformities rather than the prevention of future hand deformities. Lastly, although we identified factors that prohibit greater uptake of hand surgery in China, it is possible that there are additional barriers we did not assess.

## CONCLUSIONS

Surgical reconstruction of RA hand deformities occurs less frequently in China than in other countries. Through surveying patients and physicians, we identified obstacles to more frequent application of hand surgery. Although there is evidence that surgical treatment improves function and quality of life, its use requires patient awareness, physician expertise and collaboration, and health insurance coverage, which are currently insufficient in China. To overcome these barriers, we encourage rheumatologists to educate their patients about hand surgery and highlight the need for more robust training in RA-related procedures for hand surgeons, which can be achieved by international plastic surgery teaching. We expect that many of the financial hurdles will diminish as China's healthcare reforms continue to roll out. Finally, it is important to consider that RA patients in China represent a unique population. It is, therefore, important that as access to rheumatoid hand surgery expands, outcomes are studied and clinical practices are tailored to the cultural, socioeconomic, and healthcare environment of China.

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