



Elevating the role of carers in rheumatoid arthritis management in the Asia-Pacific region

Kevin Pile^{1,2} | Rachel Norager³ | Matthias Skillecorn³ | Kathryn A. Gibson⁴ | Sue Elderton⁵ | Wendy Favorito⁶ | Zhanguo Li⁷ | Rong Mu⁷ | Hideko Nakahara⁸ | Mitsumasa Kishimoto⁹ | Shintaro Hirata¹⁰ | Yuko Kaneko¹¹ | Chak-Sing Lau¹² | Lai-Shan Tam¹³ | Yi-Hsing Chen¹⁴ | Pearly Chen³ | Bryan Wahking³ | Daniel Furtner³

¹Department of Medicine, Western Sydney University, Sydney, NSW, Australia

²Campbelltown Hospital, South West Sydney Local Health District, Sydney, NSW, Australia

³Johnson & Johnson Pte Ltd, Singapore, Singapore

⁴Department of Rheumatology, Liverpool Hospital, Sydney, Australia

⁵Carers Australia, Canberra, Australia

⁶Arthritis Australia, Sydney, NSW, Australia

⁷Department of Rheumatology and Immunology, Peking University People's Hospital, Beijing, China

⁸Faculty of Health Science, Osaka Yukioka College of Health Science, Osaka, Japan

⁹Department of Nephrology and Rheumatology, Kyorin University School of Medicine, Tokyo, Japan

¹⁰Department of Clinical Immunology and Rheumatology, Hiroshima University Hospital, Hiroshima, Japan

¹¹Division of Rheumatology, Department of Internal Medicine, Keio University School of Medicine, Tokyo, Japan

¹²Department of Medicine, The University of Hong Kong, Hong Kong SAR, China

¹³Department of Medicine and Therapeutics, The Chinese University of Hong Kong, Hong Kong SAR, China

¹⁴Division of Allergy, Immunology and Rheumatology, Taichung Veterans General Hospital, Taichung, Taiwan

Correspondence

Kevin Pile, Department of Medicine,
Western Sydney University, Sydney, New
South Wales, Australia.
Email: kevinpile@optusnet.com.au

Funding information

Janssen Pharmaceuticals

Abstract

Aim: Carers may offer valuable insight into the true health status of patients with rheumatoid arthritis (RA). This multinational, multi-stakeholder, exploratory study in Australia, China and Japan aimed to enrich our understanding of the role and potential impact of carers on RA management.

Method: This study used a 2-phase sequential mixed methods approach involving 3 key stakeholder groups: rheumatologists, RA patients and carers. The first phase involved an in-depth qualitative exploratory survey (n = 30), which informed the development of the subsequent quantitative validation survey (n = 908). In both phases, patients and carers provided self-assessments of disease and support parameters.

Results: In the qualitative phase, patients usually understated the amount of physical support required, compared to carers. Rheumatologists underestimated the amount of physical and emotional care required, compared to carers and patients; however, in the quantitative phase, rheumatologists overestimated the level of support

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2020 The Authors. *International Journal of Rheumatic Diseases* published by Asia Pacific League of Associations for Rheumatology and John Wiley & Sons Australia, Ltd



provided by carers. Levels of support provided by carers increased as disease severity increased. Active participation of carers in clinical consultations and treatment decision-making was deemed important by 55% of all patients and 82% of all carers. All stakeholders believed carers' insights into the physical and emotional conditions of patients were useful and should be considered in clinical decision-making. Over 95% of rheumatologists reported soliciting input from the carer.

Conclusion: Carers provide valuable input that can give clinicians greater insight into the patients' physical and emotional states, and treatment adherence. Development of standardized carer-reported outcomes that correlate with patient-reported outcomes and clinical parameters will ensure clinical meaningfulness and external validity.

KEYWORDS

carer reported, holistic, patient centred, qualitative

1 | INTRODUCTION

Effective management of rheumatoid arthritis (RA) requires the coordinated efforts of a multidisciplinary team with the patient as its central focus.¹ Patient-reported outcomes (PROs) are at the core of assessing RA treatment response.² However, PROs have several limitations. To obtain accurate data, patients must be willing to provide information, and this may be influenced by factors such as the length of the questionnaire, patients' perception of usefulness, and anxiety about use of the information provided to limit services.³⁻⁵ Additionally, clinicians' perceptions of the usefulness of PROs may also impact implementation in clinical practice.^{3,5}

For patients with RA, carers may be key to addressing some of these limitations. Given their time investment, carers may offer important insight into the patient's true health status. As first-hand observers, carers may provide rheumatologists with a more complete picture of the patient's physical and emotional status. They may also help patients understand and adhere to their treatments, keep track of their appointments, follow nutritional guidelines and manage other aspects of life.^{6,7}

The role of carers is complex, and involves providing physical, emotional and financial support.^{6,7} However, studies evaluating their role in RA are scarce.^{8,9} One study in patients with RA found that patients were inclined to significantly underscore their level of pain, compared with their carers.⁸ This could affect the rheumatologist's decision to adjust the management strategy and undermine efforts to achieve optimal results, unless further information is obtained from the carer.⁸ Another study highlighted carers may help to illuminate factors that patients may not consider themselves.⁹ For instance, patients were more likely to consider intensive management acceptable if their previous treatments had failed. However, carers took into consideration the patient's past experiences of side effects, treatment duration, and response to current treatment (both emotionally and physically).⁹ This implies carers may provide rheumatologists with a more holistic view of the patient's situation.

Current management paradigms for RA tend to neglect the views of carers. This regional, multinational, multi-stakeholder, exploratory study was conducted to enrich our understanding of the roles and

potential impact of carers on RA management in the Asia-Pacific region.

2 | METHODS

2.1 | Study design

We used a sequential mixed methods approach to understand the roles of carers and the potential impact of carer involvement. The initial qualitative phase used semi-structured interviews to understand the role of carers in RA management. The key themes highlighted in this phase informed the development of the quantitative validation survey.¹⁰ This was a multinational, uni-region study conducted in Australia, China and Japan.

2.2 | Qualitative methods

The phase I survey was conducted between 14 May 2018 and 15 June 2018. It adopted a qualitative, exploratory approach using semi-structured in-depth face-to-face interviews with carers, patients and rheumatologists. Recruitment across China, Japan and Australia consisted of triads of treating rheumatologists, patients living with RA, and their carers. Rheumatologist eligibility criteria included: aged 30-65 years; currently registered and practicing; registered for ≥ 2 years; and currently treating RA patients of mild, moderate and severe conditions. Patients were eligible to participate if they were: aged >18 years; and self-assessed as mild, moderate or severe RA during recruitment. RA severity for research recruitment categorization was based on the patients' self-reported definition. Carer eligibility criteria included: aged >18 years; and had been a carer for ≥ 6 months (to include influencing treatment and care decision-making or providing direct assistance for ≥ 4 hours per day). Interview topics included: (a) RA patient journey and experiences, highs and lows; (b) role and importance of carers; (c) met and unmet needs; (d) treatment decisions; (e) adherence; (f) improving patient



outcomes; (g) supporting carers; and (h) improving care of the patient. Thematic analysis was used to extract recurring themes.

2.3 | Stakeholder insight

On 19 July 2018, a panel of experts, the “CollAboRatE Coalition”, met to provide feedback on the qualitative exploratory study findings, provide input on the quantitative validation study and advise on the approach to share the research findings and address the insights generated. CollAboRatE is a regional initiative led by a multi-stakeholder coalition of rheumatologists, patient and carer organizations across Asia-Pacific which aims to understand and elevate the role of carers in the clinical management of RA, empower carers to become involved in and contribute to treatment decisions, and build the capacity and influence of rheumatology carer and patient organizations.

2.4 | Quantitative methods

The phase II survey was conducted between 7 August 2018 and 21 August 2018. This online validation survey consisted of 3 separate questionnaires designed specifically for carers, patients and rheumatologists. Questionnaires were reverse-translated from English to Japanese and simplified Chinese (and responses to English) by professional NAATI (National Accreditation Authority for Translators and Interpreters) translators. Questionnaires were deployed via an online scripted survey approach. Respondents were pre-screened via an online screener or telephone screening. Rheumatologist eligibility criteria included self-identified as currently registered for ≥ 2 years and treating patients with RA. Patient eligibility criteria included >18 years of age and self-identified as being diagnosed with RA. Patients were further classified based on self-descriptions of severity and disease activity. Definitions of severity: mild defined as “I live an active and independent life most of the time”; moderate defined as “I sometimes require physical support”; and severe defined as “I require physical support most of the time”. Definitions of disease activity: stable defined as “My symptoms have been well managed for the last 3 months”; and progressive defined as “My symptoms have been getting worse over the last 3 months”. Carer eligibility criteria included ≥ 18 years of age and self-identified as being a carer of a person with RA. The main carer was defined as the person who provides the most physical support to someone, in managing their RA condition. Recruitment was not conducted in triads or pairs. Carers were asked to describe the current RA condition of the person they are caring for (mild, moderate or severe). The final data set was tabulated and descriptively analyzed. Responses to the same questions from patients, carers and rheumatologists were compared and contrasted. A further descriptive analysis was conducted to better understand the role of a carer in the moderate-to-severe patient subgroup.

2.5 | Ethics approval and consent to participate

No ethics approval was required as this was a quality assurance activity, which is in line with the standards and guidelines for ethics review in all 3 countries¹¹⁻¹³ as well as with the practice of similar studies published recently in the area of carers in rheumatology.¹⁴⁻¹⁷ Written informed consent was obtained from all participants in both the qualitative and quantitative studies.

3 | RESULTS

3.1 | Qualitative

In total, 30 stakeholders from Australia ($n = 12$), China ($n = 12$), and Japan ($n = 6$), participated in the qualitative exploratory survey, comprising 10 rheumatologists, 10 patients with RA and 10 carers. Each interview was conducted by a different interviewer (30 interviewers). Recruitment consisted of 3 triads (9 participants) composed of treating rheumatologist, patient and carer, and 5 pairs (10 participants) composed of patient and carer. All other participants (7 rheumatologists, 2 patients and 2 carers) were not part of a triad or pair.

3.1.1 | Role of the carer

Carers of patients with RA provided physical care, helped with medication and emotional support. Patients with severe RA required physical care “daily” while some patients with moderate RA required physical care “very often” or “most of the time”. Carers reported spending ≥ 10 hours per week with severe patients and ≥ 3 hours per week with moderate patients, providing physical care, help with medication and emotional support.

Patients tended to understate the amount of physical support required, compared to carer reports. In contrast, while rheumatologists acknowledged RA patients needed some level of emotional and physical care, they underestimated how much physical and emotional care was required, compared to carers and patients. The role of carers is described further in Table S1, with patient, carer and rheumatologist perspectives on the role of the carer expanded in Table S2.

“She is fiercely independent and if I say, “I will help you”, “no, no, it is fine, I can do it”, even though sometimes she is struggling.”

(Carer of severe patient, Australia)

“The carer is more for emotional support for mild and moderate patients... [O]nly the very severe type patients will require daily carer assistance...”

(Rheumatologist, China)



3.1.2 | Carer involvement in consultations

During initial and ongoing management consultations, rheumatologists considered carers were more likely to be present for severe patients followed by moderate and then mild patients. The behavior and attitude of rheumatologists toward carers was highly variable. Many carers stated strongly that their input, if/when taken into account by the rheumatologist during consultations, significantly improves treatment decision-making and patient outcomes. However, some carers were frustrated as their role in caring for the patient and possible contributions in treatment decision-making were not adequately recognized by rheumatologists.

"They [carers] enhance communication with doctors, help to supervise the patient and implement my medical advice."

(Rheumatologist, China)

"I basically talk only to the patient unless they have mostly no judgment ability, which is rare in cases of RA."

(Rheumatologist, Japan)

"Usually resented. They [doctors] like to tell you what the answer is but they don't have to live with it...we have to put with whatever their solution they choose, we have to cope with that."

(Carer of severe patient, Australia)

3.1.3 | Carer support

Typically, one main primary carer provided most of the care for each RA patient. All carers of severe patients and some carers of moderate patients admitted to experiencing repeated bouts of depression and physical exhaustion themselves.

"I'm very stressed. Taking care of a patient."

(Carer of moderate patient, China)

"I get very tired. I have just gone through a period of a few weeks where I didn't want to get out of bed in the morning."

(Carer of severe patient, Australia)

3.2 | Quantitative

3.2.1 | Stakeholder demographics

A total of 131 rheumatologists, 382 patients and 395 carers participated in the study. Table 1 displays the baseline characteristics of respondents from each country. Rheumatologists in the Japanese

TABLE 1 Quantitative study demographics

	Australia	China	Japan
Rheumatologists (n)	49	42	40
Gender (% female)	35%	45%	10%
Mean y in practice (SD)	11.3 (5.1)	12.5 (3.3)	17.3 (6.6)
Patients (n)	112	110	160
Gender (% female)	63%	56%	55%
Mean age in y (SD)	54.6 (15.3)	43.6 (11.5)	55.9 (12.6)
Severity			
Mild	44%	45%	83%
Moderate	41%	52%	15%
Severe	15%	3%	2%
Disease activity			
Stable	76%	84%	96%
Progressive	24%	16%	4%
Mean duration since RA diagnosis in y (SD)	8.5 (6.4)	3.9 (3.5)	11.3 (5.9)
Status of carer ^a			
Paid ^b	21%	71%	8%
Unpaid	64%	19%	88%
Mix of paid and unpaid	14%	10%	4%
Carers (n)	122	122	151
Gender (% female)	48%	65%	29%
Mean age in y	45.5 (14.2)	35.8 (9.6)	54.7 (13.4)
Severity (of RA patient cared for)			
Mild	23%	25%	56%
Moderate	57%	59%	33%
Severe	20%	16%	11%
Mean duration caring for patient with RA in y (SD)	6.4 (5.5)	5.2 (3.5)	7.5 (5.6)
Status of carer ^a			
Paid ^b	32%	56%	11%
Unpaid	58%	40%	85%
Mix of paid and unpaid	10%	4%	5%

Abbreviation: RA, rheumatoid arthritis

^aPatients and carers were not recruited in dyads.

^bBased on response to the question of whether the carer was paid to provide care for the patient with RA.

sample were on average more experienced than those in the Chinese and Australian sample (17.3 mean years in practice vs 12.5 and 11.3 years, respectively). The proportion of female rheumatologists was below 50% in all 3 countries, and the lowest in Japan (45%, 35% and 10% female in China, Australia and Japan, respectively).

The duration since RA diagnosis was longest in Japan and shortest in China (11.3 years vs 3.9 years, respectively). A majority of

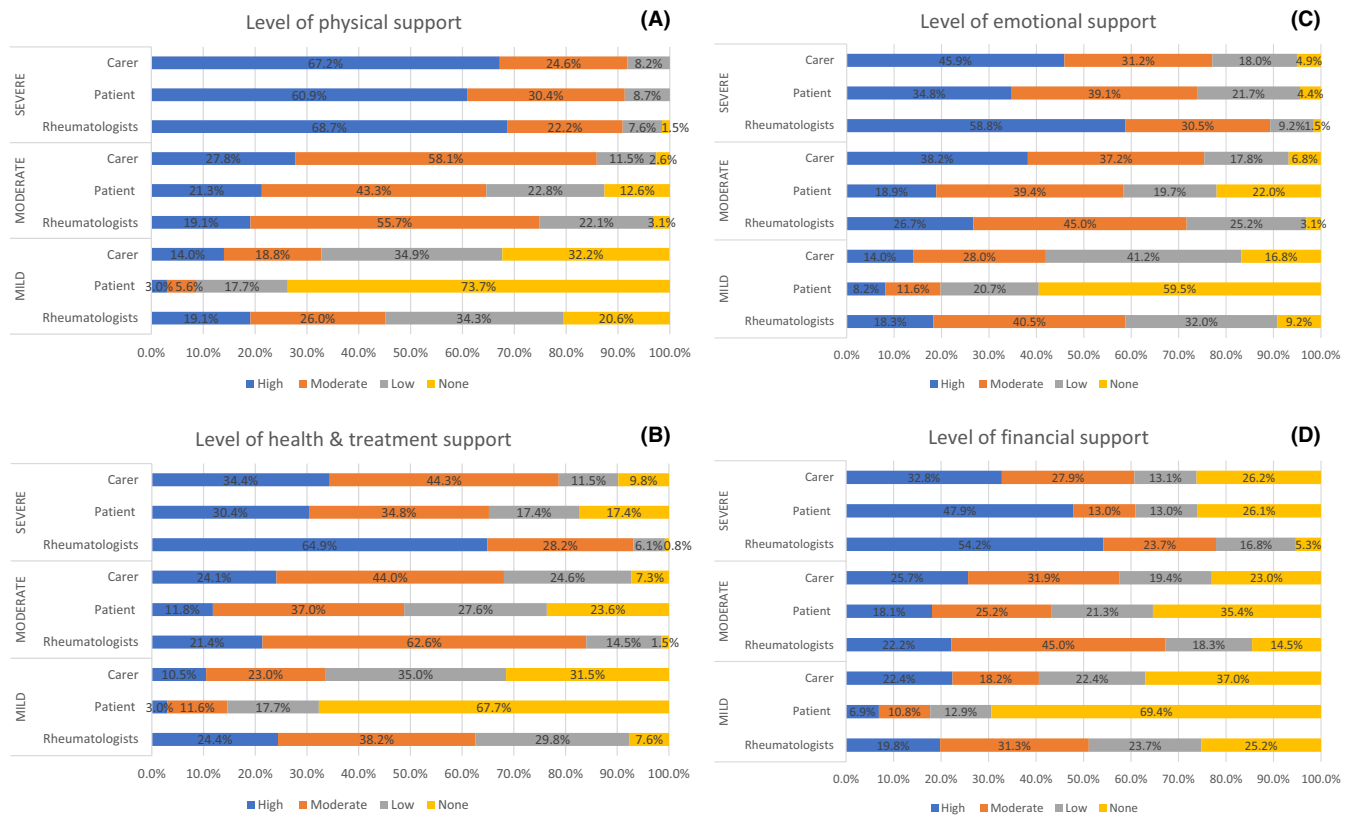


FIGURE 1 Estimates of level of support provided by the carer, received by patient and estimated by rheumatologist across all assessed domains. Patients were classified as mild, moderate or severe based on self-assessments. A, Level of physical support (such as help with personal care like washing hair, mobility such as assistance with moving around the house, meal preparation, transportation, household cleaning and cooking, shopping and buying groceries, etc). B, Level of health and treatment support (such as researching or discussing treatment options, arranging or giving medications, planning for medical appointments, reminding, encouraging and supporting the rheumatoid arthritis (RA) patient to take a medication or follow a prescribed treatment). C, Level of emotional support (such as reassuring and calming the RA patient if they feel distressed, providing support through events the RA patient is worried about, motivating and assisting the RA patient to reframe thoughts in a positive manner, etc). D, Level of financial support (such as providing household income, paying for living expenses, paying for medical expenses, etc)

the patients self-reported their RA severity as mild or moderate in Australia and China. However, in Japan, 83% self-reported their RA severity as mild and only 15% as moderate. Australia had the largest proportion of patients self-reporting severe disease (15% vs 3% in China and 2% in Japan). The majority of the patients in Japan had stable disease, followed by China and Australia (96%, 84% and 76%, respectively).

Carers in China were predominantly female whereas those in Japan were predominantly male (65% vs 29% female, respectively). Additionally, carers in China were on average younger than carers in Japan and Australia (35.8 years vs 54.7 and 45.5 years, respectively). A greater proportion of carers in China were paid, compared to carers in Japan and Australia (56% vs 11% and 32%, respectively).

A separate descriptive analysis of moderate-to-severe patients and their carers was conducted to better understand the role of the carer in this subgroup. Within this group (150 patients and 252 carers), 71% of patients self-reported their disease as stable and 29% as progressive. Among severe patients, 48% described their disease as progressive. In a country-specific analysis of moderate-to-severe

patients, 93% of patients in Japan self-reported their disease as stable, compared with 72% and 60% in China and Australia, respectively.

3.2.2 | Role of the carer

Carers reported providing the following health and treatment support to the patients they cared for: reminders to take medication; monitoring medication intake; recognizing patient's physical and emotional state; recognizing when the patient is not being truthful when describing their condition to the doctor; recognizing when a change in medication or treatment is needed; understanding treatment options; interpreting advice from the rheumatologist; and suggesting alternative treatments based on own research that have not been provided by rheumatologist. The majority of carers (76%) provided reminders to take medication; this was highest in China (96%), followed by Australia (75%), and lowest in Japan (62%). Reminders to take medication were slightly higher in the moderate-to-severe

**TABLE 2** Carer's influence on treatment decision-making

	Country			Rheumatoid arthritis severity		
	Australia	China	Japan	Mild	Moderate	Severe
Patient	N = 112	N = 110	N = 160	N = 232	N = 127	N = 23
Experienced anxiety at initial diagnosis	69%	88%	84%	78%	85%	83%
Believed education on all treatments at diagnosis would help to reduce anxiety	51%	87%	39%	47%	73%	57%
Educated on all treatment options:						
At initial diagnosis	55%	28%	31%	56%	54%	39%
For ongoing management	37%	17%	16%	69%	73%	78%
Agree carer participation in clinical consultations and treatment decision-making is important	58%	93%	27%	41%	78%	65%
Rheumatologist	n = 49	n = 42	n = 40	-	-	-
Agree education on all available treatments at diagnosis would help to lower anxiety	96%	95%	70%	-	-	-
Discuss all available treatment options:						
At initial diagnosis	96%	69%	85%	-	-	-
For ongoing management	92%	84%	80%	-	-	-
Agree carers play a role in treatment decision-making:						
For mild patients	88%	83%	72%	-	-	-
For moderate patients	100%	93%	75%	-	-	-
For severe patients	100%	95%	77%	-	-	-
Frequently solicited input from carer when they were present	98%	100%	95%	-	-	-
Carer	n = 122	n = 122	n = 151	n = 143	n = 191	n = 61
Agree carer participation in clinical consultations and treatment decision-making is important	81%	95%	52%	69%	89%	95%
Reported influencing treatment decisions for the patient they care for	61%	89%	58%	59%	72%	80%
Perceived carer input in treatment decisions to be important	81%	95%	52%	61%	83%	78%
Believed rheumatologists valued their input	80%	94%	79%	80%	85%	92%

subgroup (83%); highest in China (97%), followed by Australia (76%) and Japan (73%).

Overall, stakeholder estimates of level of physical, health and treatment, emotional and financial support provided by the carer tended to increase as disease severity increased. Carers consistently estimated the level and importance of the support they provide to be higher across physical, health and treatment, and emotional domains, compared to the level of support patients said they received (Figure 1). Estimates of time spent providing support was higher for carers compared with patients for every domain measured.

Rheumatologists consistently overestimated the level of support provided by the carer, compared with the estimates from carers and patients. However, estimates of level of physical support provided were high across all stakeholders. The support provided by carers was deemed "quite important" or "very important" by at least 1 in 2 rheumatologists. Rheumatologists considered health and treatment support to be the most important type of support provided by carers of moderate-to-severe patients. On the other

hand, patients with moderate-to-severe disease and their carers considered physical support to be the most important. In terms of financial support for patients with severe RA, rheumatologists in Japan and China estimated higher required levels of financial support than those in Australia (60% in both China and Japan vs 45% in Australia). While patients with severe RA in Australia and Japan reflected the views of rheumatologists in those countries (35% and 67%, respectively), patients in China were even more reliant on their carers for financial support (100%) than estimated by rheumatologists in China.

3.2.3 | Carer influence on treatment decision-making

Active participation of carers in clinical consultations and treatment decision-making was considered important by most of the patients and carers (Table 2). Patients and carers in Australia and China



placed greater importance on active carer participation than those from Japan. Patients reported carers could potentially help them to discuss treatment options with their rheumatologist, understand the importance of taking medications as recommended, provide reassurance regarding the treatment, understand how to take their medications correctly and help the rheumatologist to better understand their condition.

The vast majority of patients reported experiencing anxiety at the time of their diagnosis. More than half of all patients believed education on all available treatments would have helped to reduce the anxiety of being diagnosed with RA; however, this belief was more common in China than in Australia and Japan.

The majority of the rheumatologists agreed education on all available treatment options at the point of diagnosis may help lower anxiety of being diagnosed with a chronic condition. However, 28% of rheumatologists from Japan were not sure if this would be helpful (compared to 2% in both China and Australia). In current practice, more than 80% of rheumatologists reported discussing all available treatments at initial RA diagnosis as well as for ongoing RA management. However, 37% of all patients said they were not educated on treatment options available at initial diagnosis, and 23% for ongoing RA management. In the moderate-to-severe subgroup, over half of the patients reported not being educated on all treatment options at initial diagnosis and a quarter for ongoing RA management.

More than half of all carers said they had influenced treatment decisions for the patient they care for (Table 3). On the other hand, almost half of the carers in Japan (48%) believed their input in treatment decision-making was not very important, compared with 19% in Australia and 5% in China. The majority of the carers believed the rheumatologists valued their input as a carer. In the moderate-to-severe subgroup, 76% of patients considered the carer's input in treatment decision-making to be important: 93% in China, 81% in Australia and 48% in Japan. The majority of carers of moderate-to-severe patients considered their input in treatment

decision-making to be important: 98% in China, 84% in Australia and 57% in Japan. In addition, the majority of carers reported influencing treatment decisions for the moderate-to-severe patients they cared for: 91% in China, 69% in Japan and 62% in Australia. The highest levels of influence were reported by carers of patients with severe disease (80%). The majority of carers for this subgroup (87%) believed the rheumatologist valued their input as a carer.

From the rheumatologists' perspective, 98% reported soliciting input from the carer when they were present. According to rheumatologists in China, carer attendance increased as the disease severity increased. However, in Japan and Australia, higher attendance was reported for moderate than severe patients. The majority of the rheumatologists in Australia and China believed carers played a role in treatment decision-making for moderate and severe patients. However, almost a quarter of the rheumatologists in Japan considered carers had no influence in treatment decision-making for moderate and severe patients.

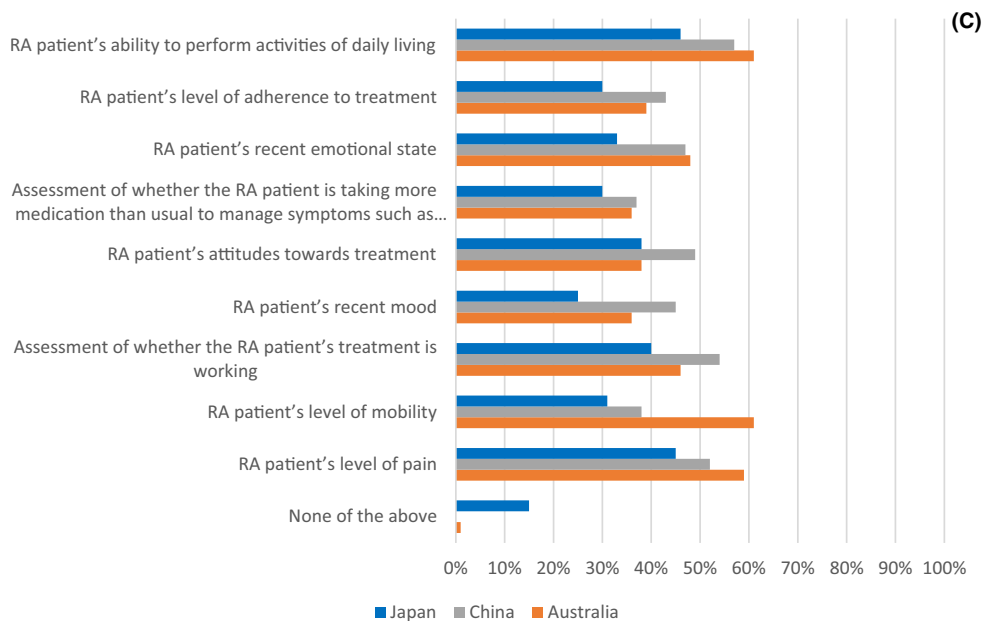
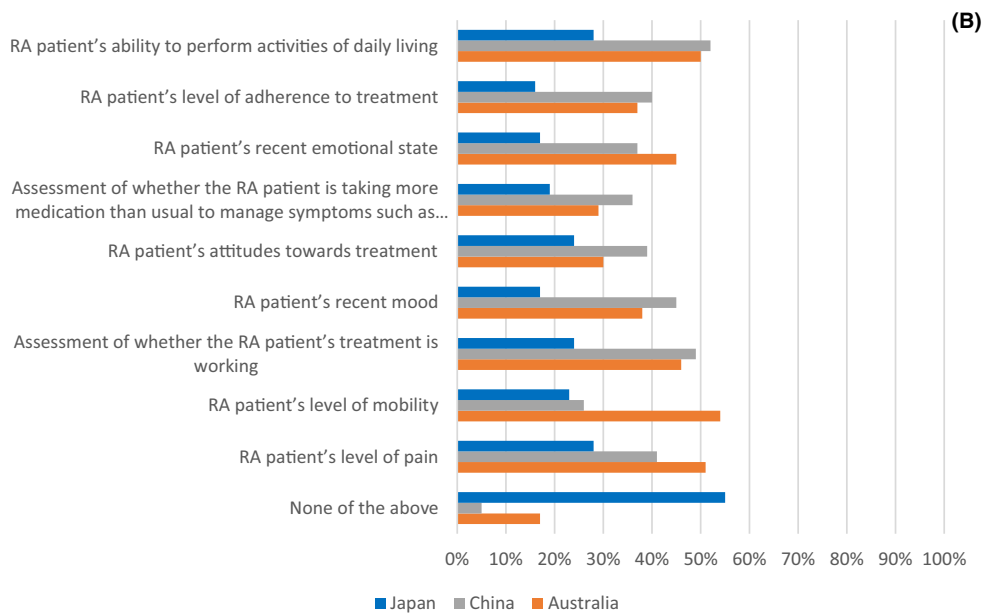
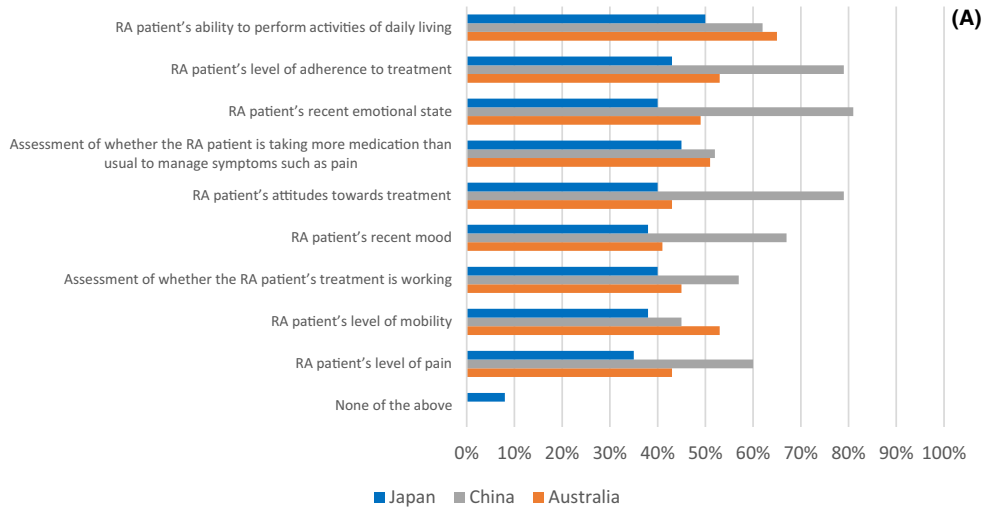
3.2.4 | Impact of carer observations

All stakeholders believed carer observations on the physical and emotional wellbeing of the patient could be valuable. Among the patients, 95% in China, 65% in Australia and 38% in Japan suggested these observations would be useful to their rheumatologists in managing their RA. Within the carer cohort, 99% of carers in China, 91% in Australia and 72% in Japan suggested these observations would be useful to the rheumatologist. Within the rheumatologist cohort, 100% of rheumatologists in Australia, 98% in China and 83% in Japan said these observations would be useful to them for managing the patient. In the moderate-to-severe subgroup, 94% of rheumatologists, 92% of carers and 78% of patients agreed carer observations of the patient's physical and emotional condition would be useful to the rheumatologist. However,

TABLE 3 Decisions influenced by carers

Treatment decision-making	Patient-reported influence			Carer-reported influence		
	Mild N = 232	Moderate N = 127	Severe N = 23	Mild N = 143	Moderate N = 191	Severe N = 61
Start a treatment regimen	26%	32%	35%	35%	31%	43%
Choose 1 treatment over another	29%	35%	26%	32%	38%	37%
Consider alternative treatment options	18%	30%	26%	29%	31%	39%
Follow the doctor's recommended treatment regimen	42%	56%	61%	38%	45%	55%
Stop following the doctor's recommended treatment regimen	10%	17%	26%	26%	28%	35%

FIGURE 2 Potentially useful carer observations for clinical management. A, Carer observations that rheumatologists believed would be most useful in the assessment and management of rheumatoid arthritis patients. B, Carer observations patients were comfortable for their carer to share with their rheumatologist while in the consultation room with them. C, Observations the carers were comfortable sharing with the rheumatologist about the patient they care for





41% of patients in Japan, 17% in Australia and 2% in China were unsure. From the rheumatologists' perspective, the top 3 most useful carer observations were the patient's ability to perform activities of daily living, patient's level of adherence to treatment and the patient's recent emotional state. Both patients' and carers' comfort levels for these carer observations to be shared with the rheumatologist were moderately high (Figure 2). However, 55% of patients in Japan were not comfortable with carers sharing any observations outlined in the study questionnaire. Overall, 44% of all patients who were uncomfortable with carers sharing any observations had mild disease, 6% had moderate and 17% had severe disease.

Carer observations may also bring a new perspective to the consultation room. The perception of disease severity differed between carers and patients. More carers described the patient they were caring for as moderate or severe, compared to patients' self-descriptions in each country.

3.2.5 | Support for carers

A quarter of all carers stated they did not receive enough support in their capacity as a carer while 18% of patients (34% unsure) and 16% of rheumatologists (21% unsure) believed carers did not receive enough support. The type of support carers considered they needed varied between countries (Figure 3). The majority of the carers preferred to receive support and information from the rheumatologist. The top places where carers sought information were the internet and the rheumatologist's practice.

4 | DISCUSSION

This sequential mixed methods study aimed to understand the potential impact of carer involvement on patients with RA and the role of carers in clinical management of RA.

Carers in the study reported providing a range of health and treatment support to the patients they cared for. However, carers consistently estimated the level and importance of their support to be higher, compared with the support patients reported receiving. This suggests patients may be underestimating the level of care they require or are receiving. It is possible that patient appreciation of carer support increases as disease severity progresses. This was reflected in the study findings as all stakeholder estimates of level of physical, health and treatment, emotional and financial support provided by the carer tended to increase as disease severity increased. It should be noted patients, carers and rheumatologists were not recruited in triads due to privacy issues. It is possible our sample included a greater proportion of carers of severe patients.

At least 1 in 2 rheumatologists estimated RA patients required moderate to high levels of support from their carer, regardless of level of disease severity (with the exception of physical support provided by carers of mild patients). For moderate-to-severe patients,

stakeholders placed different levels of importance on the types of support provided by the carer. Rheumatologists considered health and treatment support to be the most important, whereas patients and carers deemed physical support as the most important.

Rheumatologists in Japan and China estimated higher required levels of financial support for patients with severe RA than those in Australia. Interestingly, patients with severe RA in Australia and Japan reflected the views of rheumatologists, while patients in China were even more reliant on their carers for financial support than estimated by rheumatologists. This may be a reflection of the expected financial burden in these countries. In Australia, the Pharmaceutical Benefits Scheme provides universal coverage of subsidized medicines for Australian residents with a fixed patient co-payment.¹⁸ Japan also has coverage for all Japanese citizens via the National Health Insurance Scheme with patient co-payment ranging from 0% to 30% depending on the age and employment status of the patient. In contrast, China's Basic Health Insurance Scheme (BHIS) only provides basic drug coverage within a cost-containment setting.^{18,19} However, reforms are currently being undertaken to reimburse more costly medicines with the aim of reducing out-of-pocket costs for patients in China.²⁰

The majority of rheumatologists believed carers played an important role in RA management and reported soliciting information from the carer if they were present. The highest perceived values for carer input across all 3 stakeholder groups were seen in China, followed by Australia and then Japan. Patients reported carers could potentially help them to discuss treatment options with their rheumatologist, understand the importance of taking medications as recommended, provide reassurance regarding the treatment, understand how to take their medications correctly and help the rheumatologist to better understand their condition. These findings were reflected in the moderate-to-severe subgroup. The high value of carer input in China may be due to Chinese culture recognizing the high involvement of carers (ie accepting caregiving as part of life), which may then flow on into clinical practice.^{21,22} In Australia, a majority of rheumatologists and carers agreed carer observations contributed to RA management; however, only 63% of patients held this view. This may be due to Australian culture and clinical practice placing emphasis on independence and ownership of the disease.^{23,24} In contrast, almost a quarter of rheumatologists in Japan believed carers did not influence treatment decision-making for moderate and severe patients. Patients in Japan were also less likely to believe carer observations could contribute to their RA management than in China and Australia. A majority of the patients in the Japanese sample were between the ages of 18 and 50, which may have contributed to this. Younger patients are more likely than older patients to express their views and take an active part in treatment decision-making.²⁵ Furthermore, a larger proportion of the patients in the Japanese sample had mild and stable disease, compared to Australia and China, suggesting they may have required less carer input. Japanese culture also emphasizes traditional clinician-centered practice where patients rely on the clinician to make decisions about their treatment.²⁶

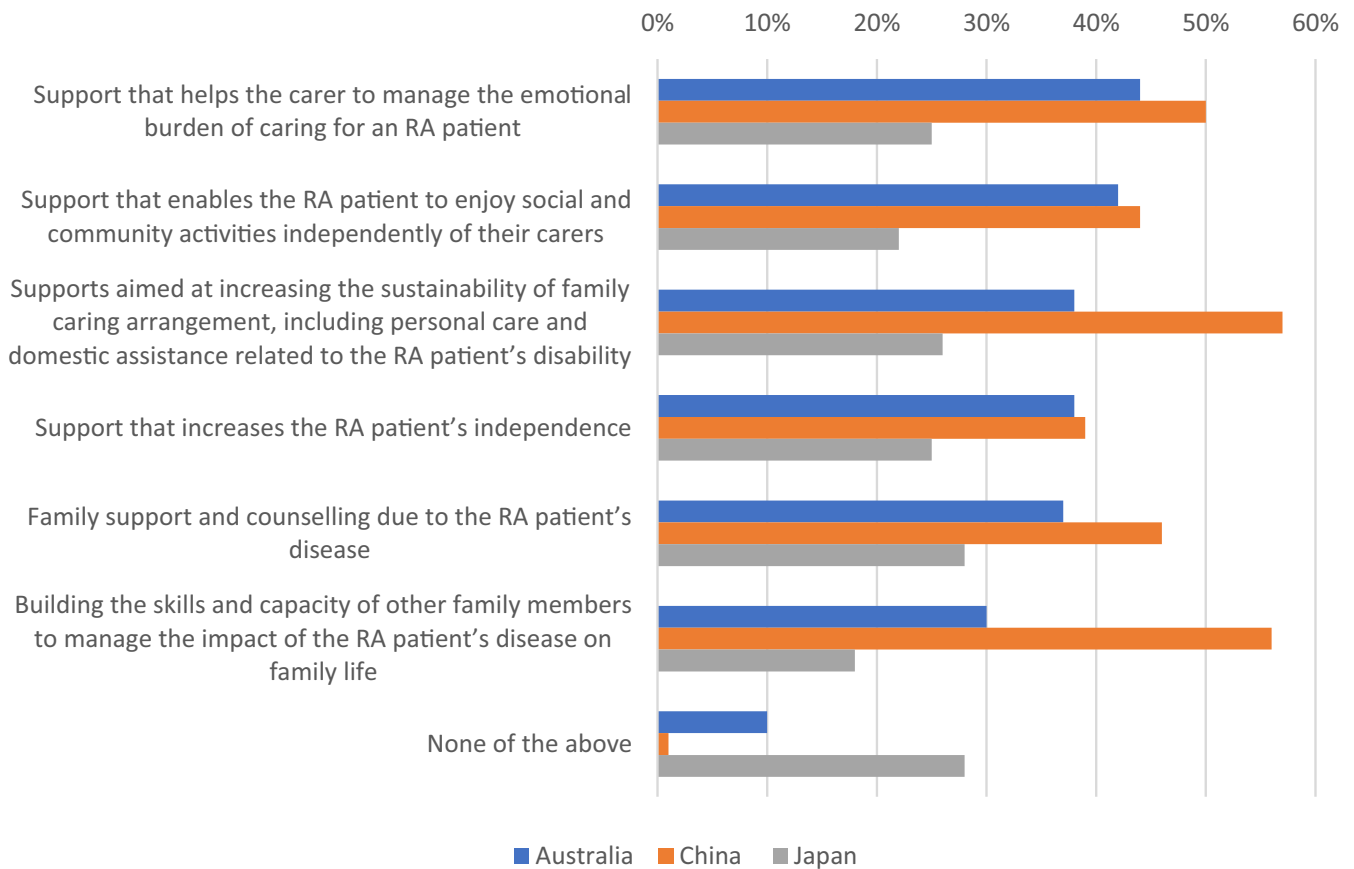


FIGURE 3 Types of support carers would like to receive in each country

Rheumatologists identified the following carer observations as useful: patient's ability to perform activities of daily living, patient's level of adherence to treatment and patient's recent emotional state. Both patients' and carers' comfort levels for these carer observations to be shared with the rheumatologist were moderately high. Patients from Australia were most comfortable with carers sharing observations relating to level of mobility, pain, and ability to perform activities of daily living, and least comfortable with observations of medication frequency and attitudes toward treatment. In China, patients were most comfortable with carers sharing observations of ability to perform activities of daily living, assessment of whether the treatment is working and recent mood, and least comfortable with observations of level of mobility. Patients from Japan were generally less comfortable with carers sharing observations than Australia and China, with 55% of patients not comfortable with any observations being shared. However, overall analysis showed 44% of all patients who were uncomfortable with carers sharing any observations had mild disease. Since 83% of the patients in the Japanese sample had mild disease, it may have influenced the finding. The large variation in patient and carer comfort levels for sharing observations seen in this study suggests a need to consider cultural sensitivities and values when gathering carer-reported outcomes.

Carers may also bring a new perspective to the consultation. In all 3 countries, more carers described the patient they were caring for as moderate or severe, compared to patient's self-description. However, patients and carers were not recruited in dyads. Despite this limitation, the data may suggest patients could be understating the severity of their symptoms. This is in line with a previous study, which found health status ratings given by carers were higher than those recorded by the patients themselves.⁸ However, 47.5% of carers in the study reported mild-to-moderate burden of caregiving, suggesting carer perception of health status of the patient may be proportional to the level of caregiving burden.⁸

Involving a carer during consultations may also help to alleviate some of the anxiety experienced by patients. On average, 80% of patients experienced anxiety at the time of their diagnosis. The proportion of patients experiencing anxiety was higher in China compared with Australia and Japan. The increased anxiety expressed by patients in China may be a reflection of the expected financial burden. In addition, the Chinese sample had a lower mean age and shorter duration of disease than the Australian and Japanese samples, suggesting they were more likely to be employed or require employment, potentially contributing to their anxiety.

In addition, more patients in China believed anxiety would have been improved if they were educated on all available treatments



at the time of diagnosis, compared with Australia and Japan. This knowledge could provide patients and their carers with some reassurance on what to expect and how to plan for the future. A majority of rheumatologists agreed providing this knowledge at the point of diagnosis could help lower anxiety of being diagnosed. However, 28% of rheumatologists from Japan were not sure if this was the case (compared to 2% in both China and Australia). This may be a direct reflection of patient expectations as only 39% of patients in Japan believed knowledge of all treatments would help to lower anxiety at the time of diagnosis.

Interestingly, despite a majority of the rheumatologists reporting provision of this information, 37% of all patients said they were not educated on all the treatment options at initial diagnosis and 23% for ongoing RA management. In the moderate-to-severe patient group, the gap was even more pronounced with over half the patients reporting not being educated on all treatment options at initial diagnosis. This disconnect between patient-reported and rheumatologist-reported provision of education may reflect the patients' unmet expectation of education and/or their failure to understand the information provided. A number of factors could affect a patient's ability to absorb the information provided, including anxiety associated with being diagnosed, how the information is delivered, use of difficult medical terminology, and so on.²⁷

Carers' influence on treatment was not limited to continuing treatments as prescribed. Patients and their carers reported carers could influence patients to stop prescribed treatments or consider other treatment options as well. As such it is important to involve carers in the treatment decision-making process and provide education so as to harness their influence to ensure the best outcomes.

All stakeholders agreed carers required some level of support. The impact of caring for an RA patient on both the mental and physical health of the carer has been previously documented.²⁸⁻³¹ The type of support carers sought varied greatly from country to country and may be a reflection of the different cultures and value systems, or different carer demographics.

This study has several limitations. Since this was an exploratory study with a small sample size, only a descriptive analysis of the data was conducted to better understand patterns in carer involvement in each country. Due to privacy issues, it was also not possible to recruit triads of patients, carers and rheumatologists. Therefore, it was not possible to draw conclusions when comparing different perspectives. The majority of the carers in the study described the patient they were caring for as moderate or severe, limiting the applicability of the results to mild patients. In addition, the lack of validated carer-reported outcomes in rheumatology or for the care of RA patients specifically was a limitation. Consequently, there was a degree of overlap in definitions of potential carer-reported outcomes evaluated in the survey (ie, "recent mood" vs "emotional state"), which may have confounded the results on the most useful carer-reported outcomes. In addition, "treatment" may have meant something different to patients and carers, compared to

rheumatologists. For patients, treatment may have encompassed holistic management.

5 | CONCLUSION

This study investigated the roles and potential impact of carers in RA management in the Asia-Pacific region. Carers play an important role in RA management by providing physical, emotional and financial support to patients, especially for patients with moderate-to-severe disease. They may also help to optimize treatment outcomes by reinforcing important information about the disease and treatment, and providing observations that may help rheumatologists in treatment decision-making.

While stakeholders considered carer observations to be valuable, they were obtained on an ad hoc basis. Development of validated carer-reported outcomes and a framework for their routine collection would facilitate their inclusion in routine consultations. Validation would require correlation with PROs and other clinical measures, and assessment of their utility. Any impact on clinician decision-making by carer-reported measures will also require investigation and careful assessment of acceptability to all stakeholders in different settings. Finally, integration of carer-reported outcomes into clinical discussions should not interfere with workflow or add to the workload of rheumatologists.

ACKNOWLEDGEMENTS

Johnson & Johnson Pte. Ltd. sponsored the study, contributed to its design, and participated in the analysis, and interpretation of the data, and in the writing, reviewing, and approval of the final version. Data collection and analysis were performed by Blue Planet Research & Consulting Pty Ltd. (Petersham NSW 2049, Australia). Medical writing was provided by Kajal Praveena Naidu on behalf of Huntsworths Health Pte Ltd. (Singapore 048941, SG) and was funded by Johnson & Johnson Pte. Ltd. This manuscript was based on work previously presented at the 2019 annual congress of the Asia-Pacific League of Associations for Rheumatology (APLAR) and has been published as a conference abstract.

CONFLICT OF INTEREST

K. Pile has received grants and personal fees from Janssen Pharmaceuticals. KA Gibson has received grants from Novartis and personal fees from Janssen and UCB. W. Favorito has received honoraria from Johnson and Johnson Services. R. Mu has received consulting fees from Xian Janssen and Johnson & Johnson Pte Ltd. outside the submitted work. H. Nahakara has received consulting fees from Janssen Pharmaceutical; speaker fees from Chugai Pharmaceutical, Bristol-Myers Squibb, Mitsubishi Tanabe Pharma Corporation, Eisai Co. Ltd, UCB, and Abbvie; and has received patent royalties from Chugai Pharmaceutical. M. Kishimoto has received honoraria from Janssen. S. Hirata has received grants from AbbVie,



Ayumi, Eisai, Pfizer, Sanofi, Tanabe Mitsubishi; and personal fees from Janssen, Abbvie, Asahi-Kasei Pharma, Asahi-Kasei Medical, Astellas, Ayumi, Celgene, Chugai, Eisai, Eli Lilly, Kissei, Novartis, Pfizer, Sanofi, Novartis, Takeda, Tanabe Mitsubishi and UCB. Y. Kaneko has received personal fees from Janssen, Abbvie, Astellas, Ayumi, Bristol-Myers Squibb, Chugai, Eisai, Eli Lilly, Hismitsu, Kissei, Pfizer, Sanofi, Takeda, Tanabe Mitsubishi, UCB and Kirin. LS Tam has received personal fees from Janssen, Abbvie, Lilly, Novartis, Celltrion and Sanofi. R. Norager, M. Skillecorn, P. Chen, B. Wahking and D. Furtner are employees of Johnson & Johnson Pte. Ltd. and may own stock/options. Y. Chen, S. Elderton, Z. Li and CS Lau have no conflicts of interest to declare.

AUTHOR CONTRIBUTIONS

All authors contributed equally to the conception and design of the study, analysis and interpretation of the data, and final approval of the version of the article to be published.

ORCID

Rachel Norager  <https://orcid.org/0000-0002-0185-9736>
 Kathryn A. Gibson  <https://orcid.org/0000-0003-2331-0311>
 Shintaro Hirata  <https://orcid.org/0000-0002-2474-9943>
 Lai-Shan Tam  <https://orcid.org/0000-0001-6410-8852>

REFERENCES

- American College of Rheumatology, Association of Rheumatology Health Professionals. Position statement: Interdisciplinary care for patients with rheumatic and musculoskeletal diseases by the rheumatology health care team. Available from: <https://www.rheumatology.org/Portals/0/Files/Multidisciplinary%20Care%20for%20Patients%20with%20Rheumatic%20and%20Musculoskeletal%20Disease.pdf> (accessed November 2018)
- Felson DT, LaValley MP. The ACR20 and defining a threshold for response in rheumatic diseases: too much of a good thing. *Arthritis Res Ther.* 2014;16(1):101.
- Bittou A, Onega T, Tosteson A, et al. Toward a better understanding of patient-reported outcomes in clinical practice. *Am J Manag Care.* 2014;20(4):281-283.
- Mercieca-Bebber R, King MT, Calvert MJ, et al. The importance of patient-reported outcomes in clinical trials and strategies for future optimization. *Patient Relat Outcome Meas.* 2018;9:353-367.
- Wolpert M. Uses and abuses of patient reported outcome measures (PROMs): potential iatrogenic impact of PROMs implementation and how it can be mitigated. *Adm Policy Ment Health.* 2014;41(2):141-145.
- Goldberg A, Rickler KS. The role of family caregivers for people with chronic illness. *Med Health R I.* 2011;94(2):41-42.
- Noonan MC, Wingham J, Taylor RS. 'Who Cares?' The experiences of caregivers of adults living with heart failure, chronic obstructive pulmonary disease and coronary artery disease: a mixed methods systematic review. *BMJ Open.* 2018;8(7):e020927.
- Bahlas S, Fathaldin O, Janoudi N, Almoallim H, Ibrahim A, Algohary S. Do rheumatoid arthritis patients rate their health status different than their caregivers? *Antiinflamm Antiallergy Agents Med Chem.* 2015;14(3):199-203.
- Prothero L, Georgopoulou S, Galloway J, Williams R, Bosworth A, Lempp H. Patients' and carers' views and expectations about intensive management for moderate rheumatoid arthritis: a qualitative study. *Psychol Health Med.* 2016;21(8):918-925.
- Schoonenboom J, Johnson RB. How to construct a mixed methods research design. *Kolner Z Soz Sozpsychol.* 2017;69(Suppl 2):107-131.
- Australian Government National Health and Medical Research Council. Ethical considerations in quality assurance and evaluation activities, March 2014. Available from: <https://www.nhmrc.gov.au/about-us/resources/ethical-considerations-quality-assurance-and-evaluation-activities> (accessed 26 January 2020)
- Xinqing Z, Wenxia Z, Yandong Z. The Chinese ethical review system and its compliance mechanisms. Available from: <http://trust-proje.ct.eu/wp-content/uploads/2016/03/Chinese-Ethics-Review-System.pdf> (accessed 26 January 2020).
- Waseda University Office of Research Ethics. Ethical guidelines for medical and health research involving human subjects. Available from: <https://www.waseda.jp/inst/ore/en/procedures/human/> (accessed 26 January 2020)
- Alten R, van de Laar M, De Leonardi F, et al. Physical and emotional burden of rheumatoid arthritis: Data from RA matters, a Web-based survey of patients and healthcare professionals. *Rheumatol Ther.* 2019;6(4):587-597.
- Gibofsky A, Galloway J, Kekow J, et al. Comparison of patient and physician perspectives in the management of rheumatoid arthritis: results from global physician- and patient-based surveys. *Health Qual Life Outcomes.* 2018;16(1):211.
- Thomas GP, Saunders CL, Roland MO, et al. Informal carers' health-related quality of life and patient experience in primary care: evidence from 195,364 carers in England responding to a national survey. *BMC Fam Pract.* 2015;16:62.
- Wang J, Zou X, Zhou L, et al. Patient satisfaction after nurse-led care in Chinese patients with rheumatoid arthritis: A China study. *Biomed Res.* 2017;28(11):4972-4978.
- Cook G, Kim H From regulatory approval to subsidized patient access in the Asia-pacific region: a comparison of systems across Australia, China, Japan, Korea, New Zealand, Taiwan, and Thailand. *Value Health Reg Issues.* 2015;6:40-45.
- Xu C, Wang X, Mu R, et al. Societal costs of rheumatoid arthritis in China: a hospital-based cross-sectional study. *Arthritis Care Res (Hoboken).* 2014;66(4):523-531.
- World Health Organization. Expanding access to high quality medicines. Available from: <https://www.who.int/china/activities/expanding-access-to-high-quality-medicines> (accessed 03 February 2020)
- Shea J, Zhang H. Introduction to aging and caregiving in Chinese populations. *Ageing Int.* 2017;42:137-141.
- Qiu X, Sit JWH, Koo FK. The influence of Chinese culture on family caregivers of stroke survivors: A qualitative study. *J Clin Nurs.* 2018;27(1-2):e309-e319.
- Vermaak V, Briffa NK, Langlands B, et al. Evaluation of a disease specific rheumatoid arthritis self-management education program, a single group repeated measures study. *BMC Musculoskelet Disord.* 2015;16:214.
- The Royal Australian College of General Practitioners. Clinical guideline for the diagnosis and management of early rheumatoid arthritis, August 2009. Available from: <https://www.racgp.org.au/FSD/DEV/media/documents/Clinical%20Resources/Guidelines/Joint%20replacement/Clinical-guideline-for-the-diagnosis-and-management-of-early-rheumatoid-arthritis.pdf> (accessed November 2018)
- Chilton F, Collett RA. Treatment choices, preferences and decision-making by patients with rheumatoid arthritis. *Musculoskeletal Care.* 2008;6(1):1-14.
- Aoki A, Ohbu S. Japanese physicians' preferences for decision making in rheumatoid arthritis treatment. *Patient Prefer Adherence.* 2016;10:107-113.
- Kessels RP. Patients' memory for medical information. *J R Soc Med.* 2003;96(5):219-222.



28. Brouwer WB, van Exel NJA, van de Berg B, et al. (2004) Burden of caregiving: evidence of objective burden, subjective burden, and quality of life impacts on informal caregivers of patients with rheumatoid arthritis. *Arthritis Rheum.* 2004;51(4):570-577.
29. Chung SW, Ha YJ, Kang EH, et al. The psychosocial status of the family members of rheumatoid arthritis patients in Korea. *Rheumatol Int.* 2016;36(5):719-724.
30. Jacobi CE. Dimension-specific burden of caregiving among partners of rheumatoid arthritis patients. *Rheumatology (Oxford)*. 2003;42(10):1226-1233.
31. Ru J, Ma J, Niu H, et al. Burden and depression in caregivers of patients with rheumatoid arthritis in China. *Int J Rheum Dis* 2018;22(4):608-613.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Pile K, Norager R, Skillecorn M, et al. Elevating the role of carers in rheumatoid arthritis management in the Asia-Pacific region. *Int J Rheum Dis.* 2020;23:898-910. <https://doi.org/10.1111/1756-185X.13893>