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関節リウマチ患者とリウマチ医の間にある意識の乖離
—アンケート調査より—

Key words: rheumatoid arthritis,
attitude,
taking care of end-of life,
ageing,
functional decline

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要　旨

目的：関節リウマチ（RA）患者の高齢化とともに生じる，意識の変化とリウマチ医の治療意識との間の齟齬を調査する目的で，開業リウマチ医（RA医）20名とRA患者1066名を対象にアンケート調査を行った．

対象・方法：質問項目は年齢階層，居住地域，開業形態（RA医）もしくは労働形態（RA患者），関節外症状対応，運動機能低下対応，認知機能低下対応，入院必要時対応，寝たきり状態の対応，看取り，イメージする医療連携の10項目で行った．RA患者とRA医の間の合致，乖離をそれぞれの項目でchi square testを用いて統計学的評価した．

結果：大部分のRA患者はかかりつけRA医（主治医）にRAだけで無く，合併症も含めた治療を望んでいた．殆どのRA医もそれに応えていた．主治医を信頼しているRA患者が殆どと思われ，入院しても主治医に診てもらいたいと望んでいた．RA患者とRA医の間の齟齬があったのは，看取りに関して，患者年齢が高くなればなるほど具体的なイメージがあり（$p<0.05$），具体的要望として主治医に看取ってもらいたいと望むRA患者が殆どであったのに対し，かかりつけRA医で看取り対応できるのは3分の1であった（$p<0.05$）．

結論：日本において，RA医は一般かかりつけ医と同様の働きを患者に求められている．開業RA医は，RA患者の老化と真摯に向き合う必要性に迫られている．

Introduction

The incidence of rheumatoid arthritis (RA) in elderly population has been increasing[1]. Currently, in Japan, most patients with RA are in their 60s and 70s[2], and age-associated problems are an important concern to rheumatologists[3]. As patients get older, their activities of daily living (ADLs) decline, and there may be accompanying attitude changes with disease longevity. Elderly patients with RA may need to alter their thoughts about what work they can do, their ADLs, lifestyle, and how they are cared for, particularly as they approach the end-of-life[4]. Accordingly, we intended to investigate these changes via interviews, aiming to clarify their thoughts about aging and terminal care. To complement this, we also identified the opinions of their attending rheumatologists in clinical practice and clarified any mismatch.

Methods

We identified a cohort of rheumatologists who belong to the Japan Association of Rheumatologists in Private practice, which is an alliance of private clinics or hospitals that were directed by a specialist of rheumatology certified from Japan College of Rheumatology (JCR), and their attending patients who were randomly selected from May 2017 to October 2017. The area of the study was widely distributed and included patients belonging to large cities and rural areas in Japan. Ten questions were asked to the rheumatologists and their patients, and the questions and their possible answers were set for being matched between rheumatologists and patients. The questions were as follows: (Question 1) personal generation; (Question 2) dwelling area; (Question 3) work status; (Question 4) how to cope with extra-articular comorbidities; (Question 5) how to cope with ADL

Table 1: Questionnaire to rheumatologist (RP) and his/her patient

Questions topics	to RP	to patient	answer choice arm
Question 1. Age	What is your age?		20s, 30s, 40s, 50s, 60s, 70s, 80s, over90 (common)
Question 2. dwelling area	In where do you live/work?		> 1 million, 1> and >0.2 million, small city>100,000, rural area (common)
Question 3. job style	What is your clinic style?	What is your job style?	clinic, with no bed, clinic with beds, hospital (RP) full time, part-time, housekeeping, no work (patient)
Question 4. Comorbidities	How do you cope with patient's/your extraarticular comorbidities including lifestyle diseases		treat directly, recommend consulting another specialized physician, recommend to consult other physician not related (RP) consult to RP, consult to other physician related to RP, consult to other physician not relate to RP (patient)
Question 5. motor function decline	How do you cope with patient's/your motor function decline		treat with rehabilitation, advise exercise with practice, advise exercise orally (RP) do rehabilitation, do exercise as RPs recommend, do nothing (patient)
Question 6. cognitive function decline	How do you cope with patient's/your cognitive decline		treat directly, recommend to consult specialized neuro/psychiatrist related to RP, recommend to consult neuro/psychiatrist not related to RP (RP) consult to RP, consult to neuro/psychiatrist related to RP, consult to neuro/psychiatrist not related to RP (patient)
Question 7. Disease severity	How do you cope with patient's/your severity in general		recommend operation, recommend admission, recommend other RPs (RP) recommended operation, recommended admission, recommended other RPs (patient)
Question 8. Bedridden	How do you cope with patient/yourself when becomes bedridden		home care service or hospital care service under RP's observation, home care service or hospital care service under other physician's observation use home care service or hospital care service under RP's observation, use home care service or hospital care service under another physician's observation
Question 9. taking care at the last moment	Do you take care of patient, or by whom do you want to be taken cared at last moment		yes, if possible, no (RP) by RP, by another physician, no image (patient)
Question 10. Ideal medical image	How is your ideal medical style for aged and functionally declined patient		single attend for every field, single attend but consulted to other specialty, multi attend for each field (common)

decline or rehabilitation needs; (Question 6) how to cope with cognitive decline; (Question 7) how to cope with status that need admission; (Question 8) how to cope with bedridden status; (Question 9) how to be taken care of in the end-of-life; and (Question 10) ideal image of medical alliance system. Further, the answers were collected; patient answers were matched to those of their rheumatologists; and the two were analyzed for mismatches. Statistical analysis was performed by chi square test. The answers of questions comprised several choices that are summarized in Table 1.

Ethical considerations

The study was conducted in compliance with the Ethical Guidelines for Medical and Health Research Involving Human Subjects of Japan and according to the principles of the Declaration of Helsinki. Protocol and consent forms were approved by the ethics committees of the affiliated institution of each RP.

Patients and their families were informed that personal information would remain anonymous and would only be used for study purposes.

Results

We included 20 rheumatologists and identified 1,066 patients. The results based on the questions are as follows:

Question 1: All rheumatologists were >50 years old, whereas the patients tended to be distributed in their fifties (19%), sixties (37%), and seventies or older (29%) (Figure 1a).

Question 2: Distributions of patient were widely spread from metropolis to country, in where there was a tendency for rheumatolo-

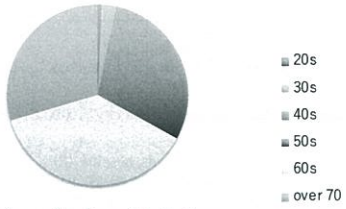

Figure 1a: Age distribution

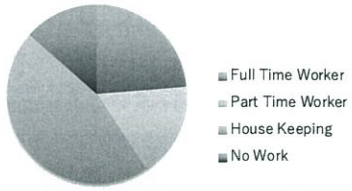

Figure 1c: Job style

Figure 1b: Resident Area

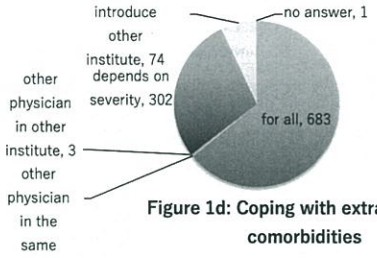

Figure 1d: Coping with extra-articular comorbidities

Figure 1: Answers to Questions 1 to 4 from RA patients
Figure 1a: Patients' age distribution
Figure 1b: Patients' resident area. megalopolis, ≥1 million ; Middle sized city, 100 ~999 thousand in population ; Small city, 30 ~ 100 thousand in population ; Rural area, < 30 thousand in population.
Figure 1c: Patients' job style
Figure 1d: By whom does patient did receive treating

gists from more urban areas to treat patients from a wider spread of residential areas (Figure 1b).

Question 3: In ≥50-year-old patients, full- and part-time work decreased, but housekeeping significantly increased ($p < 0.01$) (Figure 1c). No patients in their seventies continued work, which was significantly higher than in any of the younger age groups ($p < 0.01$). All <70-year-old patients were engaged in part-time work or housekeeping.

Question 4: Two-thirds of rheumatologist treated extra-articular comorbidities, and >95% of the patients relied on their attending rheumatologist for this treatment (Figure 1d).

Question 5: Although 74% of the rheumatologists advised a viva voce with doing nothing for a patient's ADLs decline (Figure 2a), 45% (480 of 1066) of the patients experienced functional decline in their ADLs and believed that they would benefit from rehabilitation and 99% of them (475 of 480) had received advise or prescription for rehabilitation; these results reflected on matching results of Q.5 (Figure 4). However, these opinions significantly differed between rheumatologists and patients in terms of correspondence for ADL decline; although 19 of 20 rheumatologists believed that rehabilitation is required even in the early stage, 55% of the RA patients did not consider that there is a need for rehabilitation or training ($p < 0.01$).

Question 6: Although 90% of the rheumatologist prescribed treatment for dementia after consulting with a neuropsychiatrist, 60% of the patients believed that they required no medication, even among those >70 years (Figure 2b).

Questions 7 and 8: All rheumatologists rec-

Figure 2a: ADL decline (Rehabilitation)

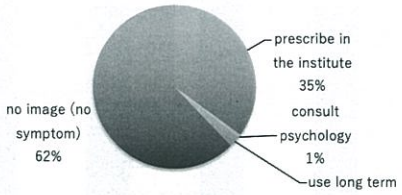

Figure 2b: cognitive decline

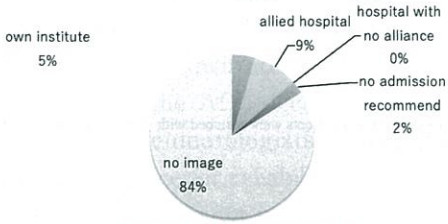

Figure 2c: Admission needed

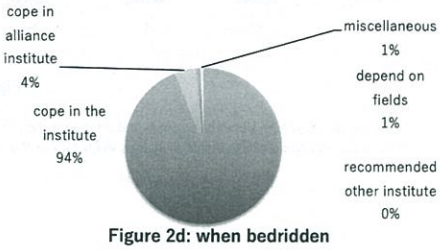

Figure 2d: when bedridden

Figure 2: Answers to Questions 5 to 8 from RA patients
Figure 2a: How patients cope with his/her ADL decline
Figure 2b: How patients cope with his/her cognitive decline
Figure 2c: How patients cope with when admission needed situation
Figure 2d: How patients cope with when bedridden situation

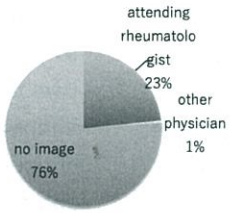

Figure 3a: by whom taken care of end-of-life

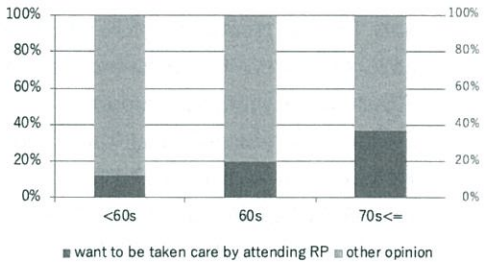

Figure 3b

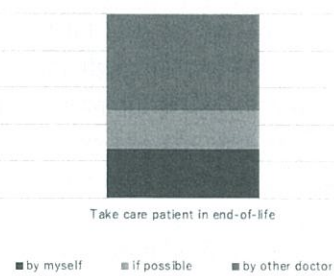

Figure 3c

Figure 3: Answers to Question 9 from patients and rheumatologists
Figure 3a: By whom RA patients desire to be taken care of end-of-life
Figure 3b: Patients' change of mind by generation
Figure 3c: Answers from rheumatologists

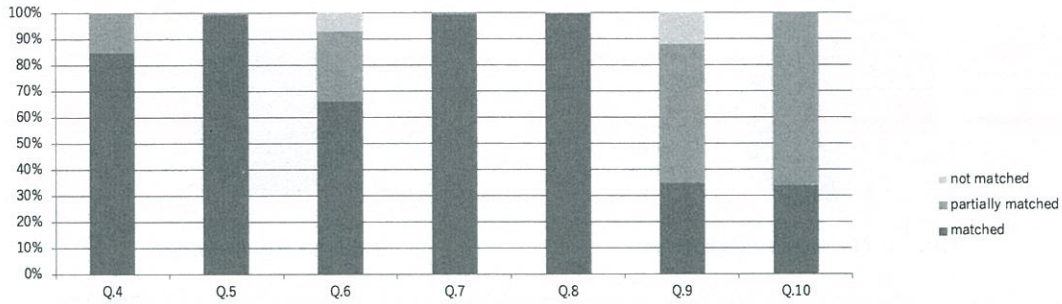

Figure 4

Figure 4: Matching and mismatching between patients and attending rheumatologists (RPs). More than 60% of patients were matched with RPs in Question 4 to 8, whereas only one third of patients were matched with RPs in Questions 9 and 10.

ommended admission or surgery for the respective scenarios, and 75% of the patients relied on and followed this guidance (Figure 2c and 2d).

Question 9: Notably, 75% of the patients had not considered receiving care at the end-of-life, yet when considering another choice, 99% wished to receive end-of-life care by their attending rheumatologist (Figure 3a). This tendency increased with age (37% in those >70 years) (Figure 3b) ; this was significantly higher than that in the younger patients ($p< 0.01$). However, only 27% of the rheumatologists responded that they would take care of patients at the end-of-life; although the answer "if possible" was included, the proportion of patients selecting this answer was 47%, which was significantly lower than what the patients wanted ($p < 0.01$; Figure 3c).

Question 10: The ideal treatment model for rheumatologists was for one physician to work in collaboration with specialists. However, only 28% of the patients shared this view.

The matching status for each question is presented in Figure 4.

Discussion

This study was inspired by a patient's feedback to the author. In this case, the patient wanted her attending rheumatologist to provide terminal care at home, which was two hours from the clinic. Accordingly, our interest increased in determining the number of patients with similar desires to receive care and that of rheumatologists who endeavored to meet these expectations.

Remarkably, >90% of the patients in this cohort relied on their rheumatologists not only for the treatment of RA but also for the care of general health, comorbidities, and ADLs. A comparable proportion of rheumatologists were able to meet these expectations. However, the wishes of 64% of the patient to receive end-of-life care from their rheumatologist did not match the opinions of their treating rheumatologist, to at least some degree. These facts may be caused, in part, by the fact that the Japanese medical system allows for free access to medical services but has ambiguous delineation among specialties.

It appears that rheumatologists in practical

settings need to be skilled in the provision of primary care. Patients with RA tend to consult rheumatologists for all their health care needs, including advice for ADL decline and cognitive decline, and rheumatologists must endeavor to respond appropriately. As a result, rheumatologists have to answer the various queries of patients; for instance, 45% of the patients who required rehabilitation or training consulted their attending rheumatologist regarding the ADL decline issue and in such cases, rheumatologists provided prescription or advice for rehabilitation. Considering that these patients increasingly rely on rheumatologists, it is not surprising that they would want to receive end-of-life care from these doctors. However, rheumatologists are often unable to meet these expectations because they have no access to beds to offer the required care. Indeed, such practice is rarely available for physicians who work in clinics in Japan, which explains why only one-third of this study's rheumatologists could provide end-of-life care. This represents an unmet need of patients with RA.

The present study has some limitations. There is no control study of questionnaire for healthy individuals or patients with other diseases. Moreover, in this study, the relationship between disease activity status and the patient's mind, or relationship with social activity were not considered. This study was mainly focused on aging and age-related mind changes. Further studies are required to clarify the relationship between the influence of aging and such patients.

In conclusion, although Japanese elderly patients with RA want their rheumatologists, similar to general physicians, to take care of their medical problems regardless of it being a specialized case of rheumatic disease, including receiving end-of-life care, this was not always feasible. This represented an unmet need that could be improved by opening the hospital system to rheumatologists.

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Conflict of interest

Authors declare no conflict of interests for this article.

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ABSTRACT

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Purpose: An interview-based study was conducted to clarify aging-associated attitude changes in elderly patients with rheumatoid arthritis (RA) and determine divergence between patients and rheumatologists in private practice (RP) in Japan.

Methods: Overall, 20 Japanese rheumatologists and their randomly chosen 1,066 patients completed a 10-item questionnaire, which configured generation, dwelling area, job status/style of RPs and patients, coping with extra-articular comorbidities, activities of daily living decline, cognitive decline, needing admission, bedridden status, end-of-life care, and identical medical alliance image. All questions were matched between patients and rheumatologists, and mismatches were statistically evaluated with chi square test.

Results: Overall, >64% of patients with RA desired that their rheumatologist, similar to general physicians, should not only treat RA but also its associated comorbidities and >90% of RPs did cope with it. Most patients relied on their attending RPs and desired to receive care during admissions. Answers that demonstrated partial mismatch between patients with RA and their attending RPs were concerning end-of-life care. In elderly patients, the image at the end-of-life is concretely configured ($p < 0.05$). In >90% of elderly patients with RA who have a detailed image for death and desired end-of-life care, only 5 of 20 rheumatologists were prepared for providing the care ($p < 0.05$).

Conclusions: Continued care up to and including death is needed in Japanese RPs such as general physicians. Japanese rheumatologists need to cope with aging problems of patients honestly.