

What do patients with rheumatoid arthritis know about their own biomedical data related to cardiovascular disease risks?

Tanaka Ngcozana^{1,2} , Kevin Corbett³ , Ajay Bhatia⁴ 

Abstract

Objective: Rheumatoid arthritis (RA) is a chronic condition characterized by articular and non-articular features. Patients with RA have an increased risk of developing cardiovascular disease. This study aimed to ascertain what patients with RA know about their numbers (biomedical data, including blood pressure, cholesterol, disease activity score-28 joints [DAS28], and body mass index [BMI]) and to understand the barriers to patients knowing these health indicators and how their knowledge can be improved.

Methods: A total of 50 consecutive patients from a clinic were approached to complete an anonymous survey in a nurse-led clinic. The questionnaire included 10 questions that assessed the demographic data, knowledge of biomedical data, importance of these data, and how their awareness could be increased.

Results: A total of 40 patients responded to the questionnaire; the estimated mean age was 58.1±13.4 (mean±standard deviation) years. Most respondents were females (87%). The highest disease category duration was 2-5 years (40% patients). Moreover, 30% of respondents were aware of the “know your numbers” concept; 90% did not know their BMI, and 75% did not know about their DAS28 score. Furthermore, 40% reported that they were not informed about their biomedical data; 95% of patients revealed that they would like to know their numbers; 27.5% suggested that a regularly updated and explained written record would be appropriate, and 35% proposed that a multidisciplinary input would be useful in regularly informing them of the numbers.

Conclusion: This study has shown that although patients are not very familiar with all of their biomedical data, they are interested in knowing them. Knowing their biomedical data may encourage them to be more concerned about their health and even lead to improved RA self-management and health outcomes.

Keywords: Rheumatoid arthritis, cardiovascular diseases, patients, knowledge

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Introduction

There has been a drive by the United Kingdom's Department of Health for patients to self-manage their health conditions as recommended in policy documents, such as “Our Health, Our Care, Our Say.”¹ Evidence suggests that supporting patients to take care of themselves can help improve their motivation, reduce their symptoms, and improve clinical outcomes. The extent to which patients eat well and exercise can also be improved along with their use of health services.² One approach to empowering patients is the “know your numbers” campaign, which was initiated by Blood Pressure UK,³ having reported that three quarters of the population had no knowledge of the most important biomedical indicators with respect to their health.

Patients with rheumatoid arthritis (RA) have a higher mortality and morbidity rate than the general population owing to an increased risk of cardiovascular disease (CVD).⁴⁻⁶ Studies have demonstrated that CVD in patients with RA is approximately 60% higher than in the general population.^{7,8} A meta-analysis of 24 mortality rate studies published between 1920 and 2005 indicated that CVD contributed to an excess mortality of 50% in patients with RA.⁹ Other studies have proposed that cardiovascular morbidity in these patients is as immense as in people with type 2 diabetes mellitus.^{10,11}

Various mechanisms have been proposed to account for the increase in CVD in patients with RA. It has been shown that suppression of inflammation using disease-modifying anti-rheumatic drugs reduces the

cardiovascular risk; this mechanism is referred to as tight control or treat-to-target with a disease activity score (DAS) of <2.6. Several traditional cardiovascular risk factors have also been identified in patients with RA, including hypertension, hyperglycemia, obesity, smoking, hypercholesterolemia, and inflammation.^{12,13}

With the increased awareness of annual screening for CVD risk identification and management in RA care,^{14,15} effective implementation of timely education for patients is necessary to achieve the best possible clinical outcomes. Informed decision-making processes between patients and health professionals are important to promote shared responsibility for care.¹⁶ When patients know their numbers, they can experience better disease control that leads to improved management of RA flare-ups and increased medication adherence.¹⁷

Although educational programs can improve patients' knowledge, few studies have looked at the knowledge held by patients about their biomedical indicators or the meaning they attribute to it. This study aimed to ascertain the knowledge held by patients with RA regarding their biomedical data, understand any barriers to their awareness or use of the knowledge, and consider how these barriers could be addressed.

Methods

The study was designed as a single cohort descriptive pilot survey conducted in one institution. Data were collected between February to April 2016. A total of 50 consecutive patients with RA seen in a district general hospital nurse-led clinic were invited to complete a questionnaire. The questionnaire consisted of 10 items, which captured the demograph-

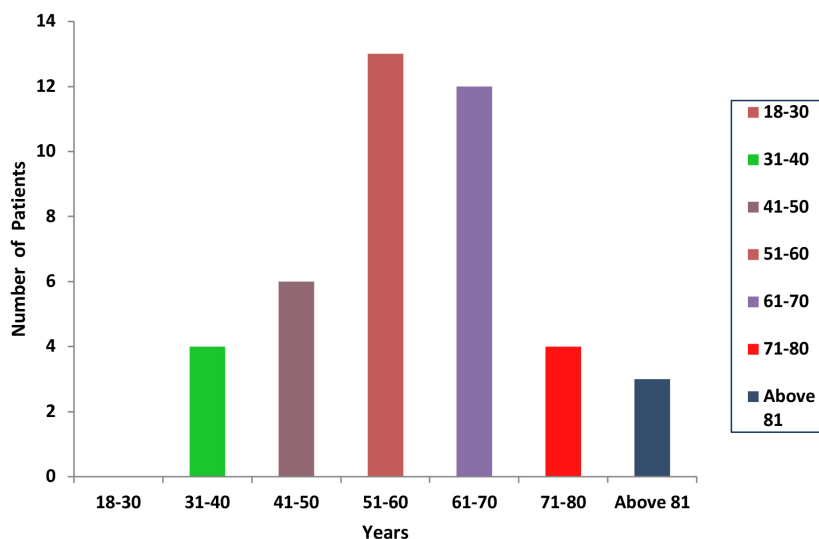


Figure 1. Sample age distribution.

Table 1. Individual biomedical data.

Responses	Blood pressure, n (%)	Cholesterol, n (%)	Blood glucose levels, n (%)	BMI, n (%)
Yes	19 (47.5)	11 (27.5)	8 (20)	4 (10)
No	21 (52.5)	29 (72.5)	32 (80)	36 (90)

BMI: body mass index.

ic data, patients' knowledge of their current biomedical data, importance of knowing their numbers, and what could be done to increase their knowledge. The questionnaire was anonymized, and a patient information sheet was used to obtain informed consent. Patients were asked to verify that they had read and understood the information with consent presumed by the return of the questionnaire. Participation was voluntary, and patients were informed that they could withdraw at any time without it affecting their treatment.

This study was approved by the East of England Essex Research Ethics Committee (Approval Date: February 4, 2016; Approval Number: 16/EE/0025).

Statistical analysis

Statistical analysis was conducted using Microsoft Excel Data Analysis Toolpak in Excel 2010 (Microsoft Corporation; Redmond, Washington, USA). Descriptive statistics were used to summarize the data. Continuous variables are presented as mean values±standard deviation (SD) and categorical data as percentage (%) values.

Results

All patients recruited into this study had been diagnosed as having RA by a rheumatology consultant according to the American College of Rheumatology criteria 2010.¹⁸ A total of 40

patients completed the questionnaire in its entirety, which represents 80% of the original sample. Results in this section pertain to those 40 patients, of which most were women (87.5%, n=35). The age distribution of the sample is presented in Figure 1. Their mean age was 58.1±13.4 years with a majority of participants aged between 51 and 70 years (62.5%, n=25). The mean disease duration was 6.8±5.7 years. The number of patients who had been diagnosed for 6-10 years and 11-15 years were the same (15%, n=6). The highest proportion of patients had been diagnosed for 2-5 years with a median of 3.5 years (40%, n=16).

Only 30% (n=12) of patients were familiar with the term "know your numbers." However, patients' responses varied when asked about their individual biomedical data, such as their latest readings for blood pressure, cholesterol, blood sugars, and body mass index (BMI).

Table 1 shows details of patients' varied responses and indicates that most patients were unaware of their biomedical data. For example, most respondents (90%, n=36) did not know their BMI. In addition, (75%, n=30) were unfamiliar with the term DAS, and 57.5% (n=23) of patients had not brought a list of their medication to their consultation, although many knew their medication by memory.

Main Points

- Knowledge of biomedical data is essential for patients with rheumatoid arthritis (RA) because of their risk of developing cardiovascular disease.
- Patients are not always familiar with their biomedical data, such as blood pressure, cholesterol, body mass index, and disease activity score-28 joints.
- Patients with RA are interested in knowing and understanding their health indicators.
- Patients' knowledge of their biomedical data can encourage more personal responsibility for health by increased engagement and activation for RA self-management.

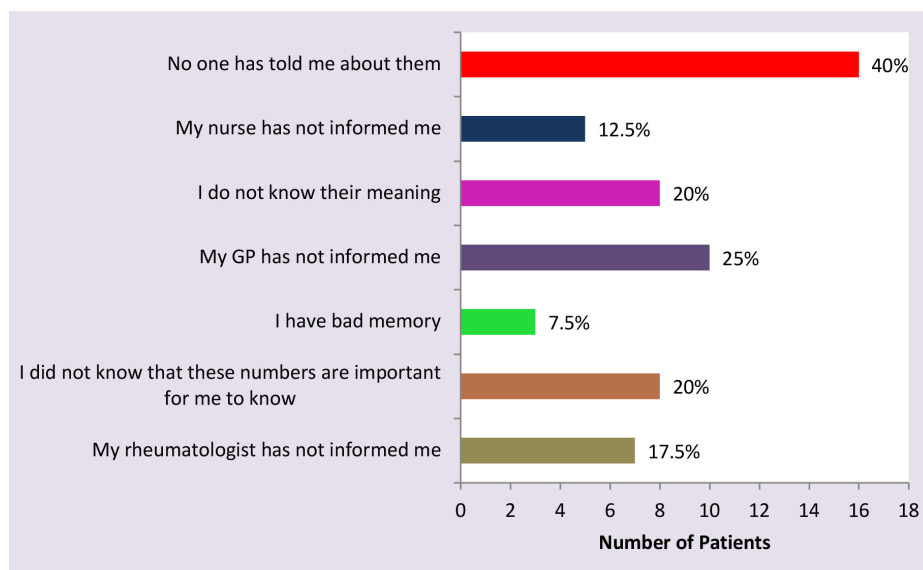


Figure 2. Barriers to appreciating the significance of biomedical data.

Regarding the significance of their biomedical data, 50% (n=20) of respondents knew about the importance of their numbers. Those who did not know were requested to circle their reason from a list of options (Figure 2), of which 40% (n=16) highlighted that no one had informed them about the importance of their numbers. A minority of patients (7.5%, n=3) responded that they had bad memory.

Most participants wanted to know about their numbers (95%, n=38), even those who already had some awareness. These respondents were asked to suggest how their numbers could be shared with them. A written record or passport of biomedical data that they could keep with them was proposed by 27.5% (n=11), whereas 35% (n=14) suggested a multidisciplinary approach that provided an explanation of their numbers every time they were seen by a healthcare professional. The remainder simply wanted someone to inform them of their numbers.

Discussion

This study aimed to find out what patients knew about their biomedical data, what the importance of that knowledge was, what were the barriers to its attainment, and how their knowledge could be improved. The study response rate of 80% was good, and participant demographics were consistent with those of published studies that show RA affects 2-3 women per man.¹⁹⁻²¹

The National Institute for Health and Care Excellence (NICE) guidance CG79²² states that patients with RA should be checked for the development of comorbidities, such as ischemic heart disease and hypertension. This is

consistent with the British Society of Rheumatology guidelines, which stipulate that patients with RA should be screened for CV risks and managed according to the findings of their assessments.²³ The European League against Rheumatism (EULAR) has recommended that all patients with RA should undergo an annual CV risk assessment using national guidelines.²⁴ They also advise that if any CV risks are identified, the patient should be managed according to local guidelines. Numerous efforts have been taken to improve the screening for CV risks, especially in a patient's annual review appointment. The EULAR has revised their recommendations in CV risk management for people with RA and other inflammatory joint diseases.²⁵

The question remains whether patients are really being educated on their CV risks and associated prevention measures so that they can take the responsibility of their health indicators. NICE guidance²² proposed that a paternalistic approach in which the healthcare professional knows the best and the patient is a passive recipient of care should be a memory of the past. Patients now need to be active participants in their own care and the related decision-making process. The National Health Service England states that patient activation is of particular importance to the 1.5 million people living with long-term conditions.²⁶

This study indicated that most patients (70%) were unaware of the term "know your numbers." Although some patients knew the result of their last biomedical measurement, a high percentage (90%) lacked knowledge of their BMI. A review has indicated that patients' perception of CVD reveals a lack of understanding

about this condition.²⁷ The Reassessing European Attitudes about Cardiovascular Treatment study has reported that a large proportion of the general population did not appreciate that CVD is one of the leading causes of death.²⁸ The study has also shown that many people underestimated their risk of CVD and most of them were unaware of the leading causes of CVD. Although these results were from a general population, our study suggested they may also be true for patients with RA. This is supported by a review that identified low awareness and perceived risk of CVD in patients with RA.²⁹ The review's authors also emphasized the need for individually tailored interventions to address any knowledge gap. Others have drawn attention to the importance of healthcare professionals and patients having the support and information needed to engage in the prevention and early detection of CVD.^{30,31} They argued that patient education promotes self-sufficiency and recommended delivery through formal sessions or other means.

A qualitative study using focus group interviews among 14 patients with RA explored their involvement in screening and management for CV risk.³¹ The study aimed to identify important issues for future screening programs, and their sample was stratified according to the level of CV risk. A prominent theme was an essential requirement for screening consultations to be adjusted to individual needs and a person's illness in context, given the significant impact RA has on someone's life. What is not clear from the study is the extent to which patients knew what their health indicators were and how to act on them once screened. When part of a risk prevention strategy, helping someone understand biomedical indicators and providing guidance for any desired change can promote patient activation.

An Australian general public health promotion project known as "know your numbers" developed a blood pressure and other stroke risk factor program, which offered participants free blood pressure checks and educational resources.³² Data were collected through a registration log and questionnaires at baseline and at 3 months. At baseline, 32% of respondents were not aware of their blood pressure status. However at 3-month follow-up, there was improvement in the participants' knowledge on 9 of 11 CVD risks factors. All participants reported 1 health promotion action, and of 510 individuals who had been advised to visit their doctor, 141 did visit.

The wider evidence indicates that imparting education and raising awareness can improve

people's knowledge of their numbers, which in turn has a potential to translate into better engagement with change in behaviors. In this study, 95% of participants would like to have known their numbers. This suggests that there is a willing opportunity to better support patients with RA through health screening, education, and risk reduction strategies. In support of these goals, the National Rheumatoid Arthritis Society has produced an online tool to encourage patient participation and engagement in their biomedical data as it pertains to cardiovascular risk.³³

This study has limitations given its small sample size, which was recruited from a single site—a district hospital; perhaps a larger tertiary hospital would have given different results. Moreover, the patients' educational levels were not evaluated, which could have contributed to the results. However, the study provides a useful snapshot of challenges and opportunities that may resonate with other local contexts and service settings. Further research with larger samples across multiple sites, which also take ethnic risk differences into account, would be beneficial.

In conclusion, CVD is one of the leading causes of mortality in patients with RA, for whom it is important to identify modifiable factors and associated risks and manage them. This study highlights the gap between patients' familiarity with the importance of "knowing your numbers" and understanding the significance of the numbers. The development of an RA biomedical data-specific record or passport would be useful to help the patients remain informed of their numbers. To avoid the passport from being just a recording tool, patients will need proactive education about the meaning and significance of their biomedical data. In turn, this can foster greater patient engagement and ownership of their health and promote self-management.

Ethics Committee Approval: Ethics committee approval was received for this study from the East of England Essex Research Ethics Committee (Approval Date: February 4, 2016; Approval Number: 16/EE/0025).

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