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Impact of socioeconomic gradients within and between countries on health of patients with rheumatoid arthritis (RA): Lessons from QUEST RA

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In this chapter, we discuss challenges in collecting data on outcomes of patients who receive usual rheumatology care. We present results of the multinational Quantitative Monitoring of Patients with Rheumatoid Arthritis (QUEST RA) study which is a successful example of quantitative clinical measuring of RA as part of routine clinical care in a large number of centres across more than 30 countries. We further elaborate on what we can learn from these data about inequalities and inequities, both within and between countries. Frameworks to understand socio-economic determinants of health are presented and, in addition to the QUEST RA data, the literature is summarised to provide further evidence on how socioeconomic determinants can contribute to health disparities of patients within and between countries.

Introduction

Clinical management and outcomes of rheumatoid arthritis (RA) have changed over the last two decades. New potent biologic treatments came to market in the late 1990s and are now widely used. Old traditional disease-modifying anti-rheumatic drugs (DMARDs) are being used more effectively. As

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a result of these changes, it has been recognised that remission is possible to be reached when treating patients early and actively [1,2]. Long-term outcomes of RA have improved compared to earlier decades concerning patient general status, disease activity, joint damage and need for joint replacements, work disability and mortality [3]. Recent guidelines and treatment recommendations emphasise early, active and continuous care of patients with RA and have been successfully communicated to rheumatology communities around the world [4]. A sense of great achievement in treatment of RA can be felt in rheumatology meetings and scientific literature.

A question remains whether this achievement is valid for all patients regardless of age, gender, race, prosperity, country of residence or economic environment. Do all patients with RA receive high quality rheumatology care in all parts of the world?

Challenges when collecting information on patients' health status in the usual care setting

Documentation of clinical status and outcomes of patients who receive usual clinical care in different rheumatology settings in different countries is needed for comparative studies between countries or between specific groups of patients. However, most clinical rheumatology care continues to be conducted according to physicians' impressions rather than to quantitative measures, which are used primarily in clinical trials and for research purposes. As clinical data are an essential element to compare data between clinics and countries, we first discuss challenges in collecting data from usual patients in rheumatology clinics.

Challenges related to study design

Neither randomised clinical trials (RCTs) nor registries describe usual clinical care. Most of the medical literature concerning quantitative measures of RA is based on RCTs for which clinical data are being extensively collected. RCTs are regarded as providing the strongest evidence on the efficacy of an intervention and they are regarded as the highest level of evidence-based medicine [5]. However, patients in trials are highly selected, and therefore RCTs do not profile usual clinical care, despite being increasingly conducted in various countries on all continents. Consequently, patients in RCTs may differ substantially from patients seen in standard care [6–8]. Also RA registers are not generalizable to all patients receiving usual care. Certainly, clinical registries monitor patients outside of clinical trials and better reflect health status of patients treated in clinical care [9]. However, they generally include only selected patients, e.g., patients with early disease or patients who receive certain therapies. Moreover, there is evidence that not all patients eligible for registers are invited and that not all patients invited will agree to participate. For example, illiteracy is a frequent reason to exclude patients from registries. There even may be bias in the centres or rheumatologists that are invited or that agree to participate in such registries. Therefore, these registers do not provide a generalizable picture of patients who receive usual clinical care.

As a consequence, to be really informed about the health status or about benefits and harms of treatments in all patients, information on unselected patients should be available as provided in clinical care. This is the only approach to generate data that can provide insight into which subgroups of patients are at risk for low health-care quality or which countries are at risk of not being able to provide recommended care.

Challenges related to choice and source of measures

Outside of RCTs and registers, most usual clinical rheumatology care continues to be conducted according to physicians' impressions rather than to quantitative measures. Two main types of quantitative measures for RA outcome assessment could be distinguished: laboratory tests and medical records.

Laboratory tests are usually the only quantitative measures collected in all patients. Outcome measures of many chronic diseases can be assessed effectively from a usual medical record through objective measurements or laboratory tests as is the case of diabetes (glucose and haemoglobin A1C), hyperlipidaemia (cholesterol), hypertension (blood pressure) and osteoporosis (bone density). These