Context matters in outcome and management of rheumatoid arthritis

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Valorization
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In this section of the thesis, the societal relevance of the work will be described. It is estimated that rheumatoid arthritis (RA) affects about 1.0% of the adult population worldwide, thus RA remains a major public health problem associated with considerable costs to the healthcare system and the society as a whole.\(^1\) Despite advancements in the understanding of the disease and availability of pharmacological treatments in recent decades, RA still cannot be prevented or cured, and remains a lifelong burden to patients. Pain, functional impairment, fatigue and depression are common symptoms of RA and interfere with patients’ participation in social activities and with overall quality of life.\(^2\-4\) To enhance equal care for all patients across countries, recommendations for pharmacological management as well as standards of care have been formulated at an international level (e.g. European League Against Rheumatic Diseases, American College of Rheumatology).\(^5\-8\) However, these recommendations mostly rely on evidence from studies conducted in a limited number of countries from Western Europe or North America. While such international recommendations and standards have the potential to improve health outcomes of patients worldwide, we should realize that they are in fact aspirational, as implementation in the different countries heavily depends on cultural and economic background. Patients with diverse socio-cultural backgrounds may differ in how they perceive the disease burden and consequently result in different treatment needs and priorities. Societies that differ in financial potential or ideology could have different needs and priorities and could choose for different solutions. In 2014, the *Lancet Commission on Culture and Health* argued that the systematic neglect of culture in health and health care is the single biggest barrier to the advancement of the highest standard of health worldwide.\(^9\)

In the present work, we investigated the role of country of residence as surrogate for a certain socio-cultural environment from the perspective of the patient but also the health care professional. On this line, our findings contribute to the understanding of the role of culture to health and healthcare at the individual and country level.

In part I of the thesis, we revealed that country has an important impact on outcomes in RA. The countries’ wealth, exemplified by the Gross Domestic Product per capita, explained only part of this observed variation. We moreover revealed a paradox, namely, patients from highly developed countries with overall good access to high quality healthcare services, have a lower (objective) disease activity but experience more fatigue and lower well-being. Although further research will be needed to fully understand (1) the role of country and (2) the paradox relationship between a country’s wealth and perception of health, the findings suggest that the country’s socio-cultural environment may contribute to the patients’ disease experience in RA. Specifically for
outcomes in RA, the present data suggest that internal and external stressors (e.g. a patient’s self-expectation or a demanding fast paced work environment, multiple social roles) play a key role in the experience of health of individuals (and populations). These insights may be of added value to patients and care givers. The thesis may contribute to the understanding of socio-cultural context in RA and support a shift in mind-set from a predominantly biomedical treatment approach, that overall applies to all patients irrespective of country or cultural context towards a broader view on care that also involves the patient’s individual socio-cultural context. Healthcare professionals may bring forward the possible influence of stressors on health perception by informing patients in the consultation room. Patients may be invited to self-reflect on possible stressors in their life as reduction of such stressors may improve health beyond what can be achieved with medical treatments. 

As the term socio-cultural context affects multiple areas of life and all health care players, awareness on the important relationship between culture and health cannot be limited to patients and their healthcare professionals alone but needs to be extended to health policy makers and society. For example, the World Health Organization (WHO) has initiated a number of initiatives to specifically involve European policy makers in the discussion on culture and health. Our findings may contribute to the understanding on how the wider socio-cultural environment of RA patients may influence their well-being and fuel discussions on how policy makers and society can create a more supportive socio-cultural environment for RA patients.

In Part II of the thesis, we additionally looked into the role of (culturally derived) attitudes and beliefs from the perspective of the healthcare professionals. As key players in most healthcare systems, their treatment decisions contribute enormously to health outcomes. Among rheumatologists, important variations could be found in how they value different treatment characteristics, i.e. economic aspects and patients’ preferences in addition to efficacy and safety, when choosing drug treatments for their RA patients. Interestingly, country of residence as well as socio-demographic background could not sufficiently explain the observed variations. However, such high variability in care decisions for a single patient already calls for attention and indicates possible inequities in care. Although patterns are not fully understood, raising awareness of the unexplained heterogeneity in care decisions and its possible impact on health of patients may already fuel discussions on possible improvements in the decision making process. Without any doubt, complexity of treatment decisions in RA care increased substantially in recent decades. To secure patient’s access to especially the new generation of expensive RA therapeutics, economic trade-offs became unavoidable, even to the wealthiest societies. While formal economic evaluations are essential for policy makers to decide at the regional/national level on availability of treatments to specific groups of patients, our data clearly show that individual physicians also make economic trade-offs
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in the clinical encounter. Our study revealed that clinicians overall consider absolute costs more important than relative cost-effectiveness data, although cost-effectiveness data are more informative to assess the economic value of a treatment. In this context, it is however relevant to understand that most health care systems support economic trade-offs based on absolute budgets, especially on the micro-level (hospitals or individual clinicians). Although this approach for management of healthcare costs partly explains physicians' preferences, it is to some extent worrisome as cost-effectiveness of a drug should be the more relevant driver of treatment decisions compared to absolute costs. In an era of increased availability of 'high cost, high impact drugs' in many disease areas, health policy makers may need to reconsider their cost-management approaches. The use of a more expensive treatment regimen may be justified when (long-term) effects such as reduced (long term) sick leaves or avoided work disability are taken into account. Breaking-up health related budget silos may further support such a shift in cost management.

Finally, it is important to emphasize that making economic trade-offs in the clinical encounter usually implies a decisional conflict. With introduction of very expensive treatment options in RA and other disease areas, clinicians increasingly face a situation in which they have to choose a treatment strategy with a possibly lower (chance of) treatment success for an individual patient to secure availability of resources for patients with higher treatment needs. Based on evidence and arguments brought forward by different disciplines and form varying stakeholders, physicians should also strive for a more shared viewpoint regarding value for money spent in healthcare. On this line, the debate can be opened whether and to what extent patients should be involved in the economic considerations when choosing treatments. Patient societies could play a key role and lead such discussion in the future.
References