

Assessing the impact of gout

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Valorisation

Valorisation

In this thesis, we aimed to contribute to the assessment and understanding of as yet underexplored aspects of outcome research in patients with gout. We already reflected on the process of valorisation, which is defined as “transferring academic wisdom to societal benefit” in the discussion of the individual chapters.

In this addendum we describe how the research performed in this thesis could provide relevant benefit for the general public and discuss some overarching societal, economical and clinical implications.

First, we contributed to the validation of several instruments to measure gout-specific outcomes, and comorbidity in patients with gout. As such, we are now able to better assess and understand the impact of the disease on functioning and health. The availability of instruments that assess relevant outcome measures in a standardized and scientifically sound manner contributes to meaningful and sustainable care when the effects of innovative medications or care interventions are being studied.

Second, we applied the validated instruments to investigate the independent influence of gout-specific characteristics and comorbidity on functioning and health from a patient’s perspective, but also on costs-of-illness and health loss from a societal perspective.

Finally, our research emphasizes the fact that gout should be seen as a chronic rheumatic, inflammatory disease and not only as an acute transient arthritis.

Societal implications

As a part of the Global Burden on Disease initiative in 2010, it was reported that the burden of gout (expressed as disability-adjusted life years, DALYs) significantly increased between 1990 and 2010¹. Parallel with this rising burden of disease, a broad range of initiatives emerged to improve outcomes in patients with gout. A key element in the evaluation of such initiatives is the extent to which they improve health and reduce DALYs (or improve quality-adjusted life years, QALYs). Health utility (summarized in a single value between 0 and 1, representing death and perfect health respectively) is considered to be the most appropriate approach to do so. Assessing overall health is not only important from the patient perspective, those who experience the disease, but also from the societal perspective, the general population that is not prejudiced and able to judge objectively.

However, to date, data on utility values and explanatory variables contributing to utility in patients with gout were very scarce. Therefore, in this thesis we have contributed to the understanding of utility values in patients with gout by completing the most commonly used and feasible health utility instruments (EuroQol-5-dimensions, EuroQol-Visual Analog Scale and Short Form-6-dimensions)^{2,3}. For example, our data show that, although there are only minor differences in the variables that contribute to lower utility values, substantial differences up to +/- 0.20 between the different instruments are certainly not exceptional. This is an important finding when utility

values are used to calculate QALYs and used in economic evaluations, as these rather large differences may lead to different interpretations of health status. It is of utter most importance for policy makers and healthcare insurers to be aware of these issues.

Economic implications

Considering the growing global economic burden of healthcare on the one hand, and the large economic burden of gout⁴, with an estimation of costs exceeding \$6 billion in the United States per year⁵ on the other hand, it becomes increasingly important to further gain insight into costs-of-illness (COI). As such, the cost analyses in this thesis provide data that can be used in economic evaluations of new (but often expensive) pharmacological treatment options or care interventions that are currently being developed and tested. Also, our comprehensive data including direct and indirect costs with non-medical resource use and productivity loss while at work taken into account, provide valuable information for policy makers and rational healthcare resource allocation in times when budgets are increasingly restricted.

Clinical implications

In addition to the above-mentioned societal and economic implications that cannot be generalized to the general population, it is important to acknowledge that this thesis also contributed to gout research in general practice. Since the management of the disease is known to be suboptimal in both primary and secondary care, we have investigated knowledge, illness perceptions and clinical practice behaviour among a group of general practitioners. Although general practitioners have excellent knowledge on the pathophysiology and signs and symptoms of acute gout and although they perceive gout as a chronic disease there were some remarkable discrepancies between their knowledge and perceptions and clinical behaviour. In particular, there was surprisingly little attention to adherence and even when adherence was checked, actions to improve inadequate adherence were rare. The findings in this thesis could be seen as a wake-up call to general practitioners to improve treatment on the one hand, but to researchers and guideline developers to improve knowledge of evidence-based treatment targets, implementing adherence interventions and tailoring up-to-date guidelines on the other hand. Moreover, it would be interesting to investigate whether better adherence will eventually reduce the economic and societal burden of the disease and improves the health of individual patients with gout.

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