



University of Southern Denmark

## 'Isn't biological treatment something healthy?'

### Lay people's perceptions of medical terms

Christiansen, Afshin Ashouri; Hendricks, R C; Primdahl, J; Roessler, K K; Andersen, T E; Hørslev-Petersen, K; Hendricks, O

*Published in:*  
Scandinavian Journal of Rheumatology

*DOI:*  
10.1080/03009742.2018.1522667

*Publication date:*  
2019

*Document version:*  
Accepted manuscript

*Citation for pulished version (APA):*  
Christiansen, A. A., Hendricks, R. C., Primdahl, J., Roessler, K. K., Andersen, T. E., Hørslev-Petersen, K., & Hendricks, O. (2019). 'Isn't biological treatment something healthy?': Lay people's perceptions of medical terms. *Scandinavian Journal of Rheumatology*, 48(3), 253-255. <https://doi.org/10.1080/03009742.2018.1522667>

Go to publication entry in University of Southern Denmark's Research Portal

#### **Terms of use**

This work is brought to you by the University of Southern Denmark.  
Unless otherwise specified it has been shared according to the terms for self-archiving.  
If no other license is stated, these terms apply:

- You may download this work for personal use only.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying this open access version

If you believe that this document breaches copyright please contact us providing details and we will investigate your claim.  
Please direct all enquiries to [puresupport@bib.sdu.dk](mailto:puresupport@bib.sdu.dk)

**“Isn’t biological treatment something healthy?” – Lay people’s perceptions of medical terms**

*Letter to the editor*

Afshin Ashouri Christiansen<sup>1,2</sup>, Rosamunde Cecilie Hendricks<sup>1,4</sup>, Jette Primdahl<sup>1,2,3</sup>, Kirsten Kaya Roessler<sup>4</sup>,  
Tonny Elmoose Andersen<sup>4</sup>, Kim Hørslev-Petersen<sup>1,2,3</sup>, Oliver Hendricks<sup>\*1,2,3</sup>

Affiliations:

1) Department of Rheumatology, King Christian X Hospital for Rheumatic Diseases, Graasten, Denmark

2) Institute for Regional Health Research, University of Southern Denmark, Odense, Denmark

3) Hospital of Southern Jutland, Aabenraa, Denmark

4) Department of Psychology, University of Southern Denmark, Odense, Denmark

\*Corresponding author: Oliver Hendricks; FAX: +45/73654092; Tel: +45/73654091;

E-mail: [ohendricks@gigtforeningen.dk](mailto:ohendricks@gigtforeningen.dk).

## Perception of Medical Terms

Rheumatoid arthritis (RA) and Spondyloarthritis (SpA) are systemic autoimmune diseases, characterized by chronic, systemic inflammatory conditions (1, 2). Even in case of successful anti-inflammatory treatment, pain and fatigue may remain active symptoms of these rheumatic disorders (3, 4). Patients with RA and SpA are confronted by the fact that their relatives, colleagues and friends have difficulties to understand the challenges they experience in everyday life (5). One challenge may be the physical reaction to the treatment itself: Biological disease-modifying anti-rheumatic drugs (bDMARDs = Biologics) work by interrupting immune system signals involved in the damage of joint tissue. These drugs suppress the immune system and adverse events, such as serious infections, may occur (6). In Scandinavia and several European countries, the word “*biological*” is often associated with healthy nutrition or natural products. Thus, lay people may associate the treatment based on Biologics as positive and uncomplicated. Society’s misunderstanding of the meaning of medical terms used in the rheumatic context might thus contribute to an underestimation of the burden of these diseases.

Therefore, our study investigated lay peoples understanding of medical expressions. The study was carried out by the Department of Rheumatology, King Christian X Hospital for Rheumatic Diseases, and conducted in the Region of Southern Denmark during 2017. The results are partly based on the answers given by municipally-employed staff. Participants were asked to spontaneously provide three associations to the following six medical expressions (presented in Danish): *rheumatoid arthritis*, *spondyloarthritis*, *cancer*, *biological treatment*, *chemotherapy*, *immunotherapy*. In addition, demographic and social characteristics of the participants were collected: *age*, *gender*, *education level* and *household income*. The analysis of the responses was inspired by Kvale and Brinkmann’s meaning condensation.

In all, 77 (47.5%) participants responded to the 162 distributed questionnaires. [Figure 1](#) shows the most frequent associations with the six selected medical expressions. Cancer had a strongly negative symbolic value, and more than half of the participants described cancer as “dangerous” (54.5%) and to be associated with “death” (53.2%). Pain was described as an indicator for RA (76.6%) and SpA (66.2%). However, these diseases were not perceived dangerous. The word “chemotherapy” was associated with strong side effects

## Perception of Medical Terms

(54.5%) or directly classified as “poison” (24.7%). The preconception of biological treatment differed from chemotherapy: None of the participants described biological treatment as a dangerous or hazardous treatment, while 44.2% associated biological treatment with “herbal medical product” or even as something “healthy” (36.4%). Almost half of the participants (44.2%) did not know the medical term Immunotherapy.

The Danish national rheumatological quality database (DANBIO) reports that 84% of RA patients receive effective treatment (7) – in terms of successful control of the inflammation. Nevertheless, a well-treated pain situation, i.e. a patient-reported outcome measurement (PROM) of the pain < 33, as measured on a visual analogue scale (VAS) ranging from 0-100, is achieved in only 57% of these patients (7).

The International Association for the Study of Pain (IASP) defines pain as “*An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*”. Pain and fatigue can be reported by the patient in terms of PROMs, but cannot be measured and objectified, and may be invisible for patients’ relatives and social networks. Patients report that family and friends do not recognize their illness and perceive them as being healthy (8). This ambiguity is further emphasised by the pharmacological treatment with “*biologics*”. The term “*biology*” is attributed a positive value in the common understanding in Scandinavia and several European countries and “*bio*” is the root of the word that refers to the English word ‘organic’. The semantic value of the medical phrase “*biologics*” contrasts with the rheumatological patient’s experience. Cancer diseases are feared and associated with severe illness and death (9). These associations were confirmed in the present study.

In conclusion, this study illustrates a possible impact of the language – more specifically, the semantic value of medical key words – on the perception of the rheumatic diseases RA and SpA. This may not only affect the patient’s experience of the situation, but also the patient’s expectations for the future as well as the perception among relatives, colleges and friends (10). It can be hypothesized that the semantic value of the medical phrase “*biologics*” can influence the municipally employees’ assessment of the patient’s disease

## Perception of Medical Terms

experience. In the given context, this could unintentionally affect the allocation of economic resources for the patients.

## References

1. Aletaha D, Neogi T, Silman AJ, Funovits J, Felson DT, Bingham CO 3rd et al. 2010 Rheumatoid arthritis classification criteria: an American College of Rheumatology/European League Against Rheumatism collaborative initiative. *Arthritis Rheum* 2010;62:2569-81.
2. Rudwaleit M, Landewé R, van der Heijde D, Listing J, Brandt J, Braun J et al. The development of Assessment of SpondyloArthritis International Society classification criteria for axial spondyloarthritis. *Ann Rheum Dis* 2009;68:770-6.
3. McWilliams DF, Walsh DA. Pain mechanisms in rheumatoid arthritis. *Clin Exp Rheumatol* 2017;35 Suppl 107:94-01.
4. Garrido-Cumbrera M, Hillmann O, Mahapatra R, Trigos D, Zajc P, Weiss L, Bostynets G, Gossec L, Coates LC. Improving the Management of Psoriatic Arthritis and Axial Spondyloarthritis: Roundtable Discussions with Healthcare Professionals and Patients. *Rheumatol Ther* 2017;4:219-31.
5. Primholdt N, Primdahl J, Hendricks O. A Difficult Diagnosis: A Qualitative Study of the Daily Lives of Young Men Diagnosed with Ankylosing Spondylitis. *Musculoskeletal Care* 2017;15:140-9.
6. Cañete JD, Hernández MV, Sanmartí R. Safety profile of biological therapies for treating rheumatoid arthritis. *Expert Opin Biol Ther* 2017;17:1089-03.
7. DANBIO. The Danish nationwide clinical register for patients with rheumatoid arthritis: Annual Report 2016 (<https://danbio-online.dk>). Accessed 3 April 2017.
8. Dagfinrud H, Vollestad NK, Loge JH, Kvien TK, Mengshoel AM. Fatigue in patients with ankylosing spondylitis: A comparison with the general population and associations with clinical and self-reported measures. *Arthritis Rheum*. 2005 Feb 15;53(1):5-11.
9. Bausewein C. Thinking from the end – Does the diagnosis "cancer" make a difference to patients and carers? *Z Evid Fortbild Qual Gesundheitswes* 2013;107:136-9.
10. Kirsch I. How expectancies shape experience. Washington, DC: APA Books, 1999.

## Perception of Medical Terms

**Figure 1. Most frequent associations with the six selected medical expressions**

