

The role of narratives and alternative pain-assessment tools for patients with endometriosis: A corpus-based study

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Endometriosis affects 190 million women in the world (World Health Organization 2023), but it has been addressed by healthcare institutions and society only in recent years. A key role in the official recognition of the disease is played by the illness narratives that for a long time have neither been told nor listened to and now call for acknowledgment. Literature on the topic (Bourdel et al. 2015; Gater et al. 2020) shows that during medical interviews women suffering from endometriosis are mainly asked to assess their pain on a quantitative basis, through numbers on a scale. But Drabble's (2021) approach, based on the idea of *constellations of pain*, includes other variables such as comparisons with harmful sensations, which not only vary from woman to woman but also avoid levelling up subjective illness experiences as scales may do. To narrow these gaps of (unshared) information, the following research question will be discussed in this study: can knowledge of and care for endometriosis be improved through a narrative-medicine-based approach, focused on the physician's expertise as much as on the patient's and the caregiver's story of their illness experience (Charon 2004; Fioretti et al, 2016)? To this purpose, a collection of endometriosis stories in Italian, English and German, spontaneously shared on blogs of patient associations, was analysed in a corpus-based study, using a qualitative research approach. On one hand, based on linguistic patterns such as word frequency and collocations, the analysis shows trends to a symbolic and non-quantitative description of pain in patients' stories. On the other hand, it sheds light on unexpected topics related to gender-based bias in medical discourse and to the invisibility and unreliability of patients' narratives at a social level. Besides, multilingual narratives offer a comparative sociolinguistic perspective on how endometriosis pain is symbolically expressed according to different languages and cultural backgrounds. The results obtained from the corpus analysis might help to develop non-quantitative, even non-verbal pain description and assessment tools (e.g. based on augmentative or alternative communication) that can be used *along with* the currently validated tests. This would allow long-silenced women to talk about their experience in their own way and provide valuable insights into the complexity and variety of endometriosis-related pain.

References

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