Endometriosis, characterized by the presence of endometrial implants outside the endometrial cavity, is a chronic disease affecting approximately 10% of women worldwide. Given its extensive impact on the patients’ quality of life, it is surprising how little attention has been given by the medical profession to exploring the mechanisms used by endometriosis patients to cope with this disease. One such important mechanism is the use of Computer Mediated Communication (CMC).

This qualitative study focuses on the use of online support groups by patients afflicted with endometriosis. Two online groups were accessed, and a total of 1735 posts were analysed using content analysis in an attempt to understand how the patients used the groups and what matters they discussed.

Patients reported significant negative experiences with doctors because they felt their doctors did not believe their illness narrative. This resulted in alienation from the medical community, mistrust and anger towards their clinicians. Patients therefore searched for legitimization and support from the online support group as well as medical information from each other in patient-to-patient consults. This medical information may at times be factually inaccurate, may lead to delay in accessing medical care, and changes in medical decisions.

Endometriosis peer groups may be an important adjunctive measure in the armamentarium of endometriosis treatment. It is not clear why patients feel their doctors do not believe them. Further research is needed to improve doctor-patient interactions in this area.