option for the patient but seem utterly overwhelming to the informal carer.

Conclusions The ‘drive to discharge’ causes a burden to the informal carer, which is exacerbated by a focus on patient-centeredness rather than the patient/carer intersection.

Impact This piece of work has significant importance for both older people living with frailty who are at the end of life but also their informal carers. It highlights causes of inequity and injustice during the discharge process at the end of life, and suggests how policy and practice could use relational ethics to improve outcomes and experiences through care planning and carer support.

REFERENCES

HEALTH-RELATED QUALITY OF LIFE IN ADULTS LIVING WITH EHLERS-DANLOS SYNDROME: A SYSTEMATIC REVIEW AND META-ANALYSIS INVOLVING 8251 PATIENTS


Aims The purpose of this study is to perform a systematic review of the existing literature on health-related quality of life (HRQoL) in EDS patient populations and to corroborate the association among observed variables.

Methods Four electronic databases were used to identify papers on HRQOL in adults with EDS (Scopus, Medline (by Pubmed), Epistemonikos, and Web of Science). A random-effects meta-analysis was also performed on the 36-item Short Form Survey (SF-36) measure.

Results We contained 37 studies that fulfilled the inclusion criteria. According to the SF-36 meta-analysis, EDS patients and the general population had significant differences in all criteria. According to the SF-36 meta-analysis, EDS patients and the general population had significant differences in all criteria.

Conclusions Individuals with EDS have significantly lower HRQoL in all aspects compared to the general population, with the physical component of wellbeing being the most pronounced disparity. Future research should look into the impact of different patient characteristics, evaluate the complications of EDS and their effects on wellbeing, and develop multiple intervention strategies to improve HRQoL.

Impact Due to the reduced HRQoL encountered by people with EDS, assessing QoL is critical for improving care for those suffering from this lifelong disorder. The evidence can be used to improve treatment implementation, such as using a specific instrument based on patient experience, evaluating EDS complications, and creating different non-pharmacological strategies to ameliorate difficulties related to EDS.