

# Surgical Outcomes in Patients Diagnosed with Ehlers-Danlos Syndrome: A Retrospective Review

**SURG** | Natural Sciences and Engineering (NSE) | Tags: Qualitative Data Analysis, Quantitative Data Analysis

*This cover page is meant to focus your reading of the sample proposal, summarizing important aspects of proposal writing that the author did well or could have improved. **Review the following sections before reading the sample.** The proposal is also annotated throughout to highlight key elements of the proposal's structure and content.*



Proposal Strengths	Areas for Improvement
The proposal moves from a broader topic to specific issues to the precise aims of the research.	A timeline would be useful in the methods section to support the feasibility of your project.
The researcher explicitly identifies gaps in knowledge and makes claims for why it is important to fill these gaps using evidence from past research to support their assertions.	We encourage you to include specific course numbers when talking about your coursework while you are demonstrating your relevant skills in the preparation section.
The methods address access to the data required for the study.	Some jargon is used. You must write to a broad audience in your proposal.
The researcher describes how data will be analyzed and includes "metrics of success" that show how the researcher will know when the research question has been answered. This description indicates the researcher is capable of interpreting their results, and that these methods are the appropriate methods to answer the research question.	



Other Key Features to Take Note Of
SURG proposals do not require IRB submission at time of application. However, the students must include CITI Training Certificate in Social and Behavioral Research in the appendix of their grant application; this appendix was removed from the sample grant for anonymity. Please see the Human Subjects Research section of our website for additional details.
Depending on the institution, there may be additional levels of red tape beyond IRB. For instance, at Feinberg it may be problematic to access current patient charts/data within the hospital system unless you are a paid employee. Be aware of these potential limitations and discuss early with your faculty mentor.
This project was endorsed by a faculty member outside of Northwestern University. URG sponsors/endorsers can be anyone with faculty standing even outside of Northwestern, but you must request a guest netID from the OUR director no later than one week prior to the deadline. In your proposal, you should discuss why the sponsor is a good fit for your project.

The focus of the project is clear within the first paragraph

Ehlers-Danlos Syndrome (EDS) is a clinically and genetically heterogeneous group of underdiagnosed heritable connective tissue disorders with varying physical manifestations that is estimated to impact 1 in every 5000 people (Pauker & Stoler, 2016). It is primarily characterized by joint hypermobility, often subluxation and dislocation, and hyperextensible skin, amongst other issues. Surgery has been used historically in Ehlers-Danlos to try to remedy instability of various joints, especially when more conservative treatment like physical therapy strengthening and bracing have been exhausted. Current literature has not adequately addressed the surgical concerns faced by many Ehlers-Danlos patients. There is little data on incidence, outcomes, and how this group of disorders affects quality of life, especially pertaining to orthopedics. Specifically, not enough is known about whether surgery is an effective treatment for these patients. My project seeks to understand orthopedic surgical outcomes in patients with Ehlers-Danlos Syndrome by doing a retrospective chart review at the Hospital for Special Surgery, the number one orthopedic hospital in the country. I will be able to assess the effectiveness of surgery in helping these patients' pain, quality of life, and condition. This study will shed light and aim to improve standards of care for this underdiagnosed and underrepresented population.

Logical flow from broad topic to narrow focus

There are evident gaps in knowledge of orthopedic surgical outcomes in patients with EDS. The only article available on joint surgery in EDS patients is from 1999, and outdated considering the reclassification and genetic breakthroughs that have been made since that time (Weinberg, Doering, & McFarland, 1999). Further, the survey only asked general questions: what body part, stability rating, pain rating, and ROM values. Without looking deeply into pre-operative, intra-operative, and post-operative reports through a chart review, no definitive conclusions can be made about the effectiveness of surgery in patients with EDS. The only other general surgical article is from 1969, and doesn't address orthopedic surgery specifically (Beighton & Horan, 1969). There is no literature that deals specifically with complications in orthopedic surgery in this population, only literature on pediatrics or cardiovascular surgery (Amjad, Hajivassiliou, & Pope, 2014; Freeman, Swegle, & Sise, 1996).

Identifies gap in knowledge

Justifies why gap should be filled

Identifies gap in knowledge

Justifies methodology in terms of how it helps to fill gaps in knowledge/address research aims

Considering orthopedic surgical concerns are some of the most important problems facing this patient population, and I will investigate this through a retrospective chart review. By using this methodology, I will be able to study a variety of sub-questions in my ultimate goal of assessing patient outcomes in surgery. It is necessary that it be investigated in this manner to be able to study many patients in depth, and ultimately close the gaps in knowledge in the scientific community. This paper will serve as a guide for physicians and surgeons treating EDS about whether operating is the best thing for the patient.

First, Dr. Raggio will help me to build a patient population by gathering participants through her department and her surgical colleagues who treat EDS. Once I have names of patients with confirmed Ehlers-Danlos diagnoses who have had surgery at the Hospital for Special Surgery, I will have access to their personal health information and to their charts through HSS IRB/Study #2017-1697. I will also have my own account to access the online patient portal, Epic. In order to organize my data and identify my target information, I will de-identify the patient data and go through each chart and collect pre-operative data, such as: gender, age at surgery, pre-existing conditions, allergies and medications taken prior to surgery.

Addresses access to patient data

In order to determine if the surgery was effective, I will collect data on a full physical exam including: Beighton score (a measure of joint hypermobility), range of motion (ROM) for all affected joints, nerve sensitivity, and muscular strength. This data allows me to assess the patient's condition before surgery as a baseline for comparison. Further, I will be gathering data points on history of: surgery, dislocation, recurrent soft-tissue injuries, tendon rupture, bracing,

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functional ability. In order to have a baseline comparison, I will enter and acquire copies of all testing done such as X-Rays, MRI, DEXA (bone density) scans, and genetic testing. X-Rays specifically will enable calculations of scoliosis angles, and joint alignment before and after surgery.

Next, in order to assess the outcome of the operation, I will be analyzing patient records for specific pre-op complaints, any interventions taken prior to surgery like physical therapy, and if so, gathering the physical therapy notes. I will be gathering anesthesia records, intra-operative complications, post-operative complications, and putting these into binders organized by participant ID number, and entering the relevant, extracted information into a locked excel file. I will look at what type of surgery it was (soft tissue, bone, full joint replacement), what general body part, if they had revisions to the surgery, and how many surgeries that person has had on that joint/body party specifically.

In order to determine if there was significant improvement in the patient's condition after surgery, I will analyze post-op complications such as clotting, infection, or wound healing, as patients with EDS suffer from hyper-extensible skin. I will be comparing pre-and post-op ROM values in order to determine if there was a change in mobility of the joint, as one of the main goals of surgery in the EDS population is to stabilize joints from hypermobility and dislocation. So, where a decrease in mobility would indicate a successful outcome, an increase in mobility would indicate an ineffective surgery.

Additionally, I will group my study population into those who had post-op complications and those who did not. Because of the projected size of my study population, a complication will be classified as anything out of the ordinary in the study population. As an example of the comparison between patients with and without post-op complication, I will look at the percentage of people who had complications with soft tissue surgery, bone surgery, and total joint replacements. I will then compare those percentages to the average population. I will run average and standard deviation tests, and t-tests to determine if these comparisons in complication rate are significant. I will use this information to write a report for the medical community.

As an intern for Dr. Raggio in summer 2017, I read over 150 scholarly articles and studies on EDS, and wrote detailed review of the orthopedic components of EDS organized by type of EDS. This enabled me to have a thorough background knowledge that allows me to understand the problems facing this patient population. Further, last summer I worked on the Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC) surveys. I administered the surveys to patients and did the data entry and analysis by running comparisons within different ages, genders, conditions, and within condition by specific subtype diagnosis using average, standard deviation, and t-tests. My work on the surveys, in conjunction with Statistical Methods in Psychology class at Northwestern, has given me the ability to be able to analyze the data gathered from patient charts. Finally, my own experience having orthopedic surgery has given me the compassion to understand how difficult surgery can be for patients, and has motivated me to try to help these patients by determining if surgery is the best option for their treatment. Researching this topic and gaining further exposure to the medical field directly relates to my greater academic goals of becoming a pediatric orthopedic surgeon specializing in skeletal dysplasias and orthopedic concerns as a result of special needs, like cerebral palsy or achondroplasia. Beyond understanding a disease biologically, I want to conduct research that will directly help my patients.

Methods are defined and justified explicitly in terms of how each step helps to answer the research questions

A Timeline would be helpful

Clear plan of analysis is described and connected to address research aims

Metrics of success are given

Include course numbers

Explains connection to non-NU faculty

## BIBLIOGRAPHY

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