

# Identifying the Prevalence of Decisional Conflict and Decision Regret and Analyzing Qualitative Experiences for Patients Who Have Undergone Extremity Amputation: A Systematic Review and Meta-Analysis

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## INTRODUCTION:

The decision to amputate is among the most difficult decisions faced by both orthopaedic surgeons and patients alike due to the significant morbidity and impairment inherent to the procedure. Because of this, patients may experience decisional conflict (DC) regarding the decision-making process leading to amputation, as well as decision regret (DR) regarding their outcomes following amputation. This study aims to assess the prevalence of DC and DR, as well as to identify themes in patients' qualitative experiences to better understand the decision-making processes of patients who have undergone amputation and identify ways in which surgeons can enhance decision-making and reduce patient distress.

## METHODS:

Our study design is a systematic review and meta-analysis. A literature search was conducted using terms related to "decisional conflict" or "decision regret" and "amputation" to identify relevant studies in four databases (Medline, Web of Science, Embase, and PsycINFO). Included studies were quantitative, qualitative, or mixed-method studies assessing patients' regret experiences who had amputations for any indication. Excluded studies were articles in languages other than English and case reports. None of the included quantitative studies used validated scales to measure DC or DR; we therefore identified DC and DR based on the similarity of each study's questionnaires to questions present in the Decisional Conflict Scale (DCS) or Decision Regret Scale (DRS). The prevalences of DC and DR in individual studies were calculated using a logit-transformed generalized linear mixed model (GLMM) with random effects, and a GLMM with random effects was used to estimate the pooled prevalences of DC and DR. Qualitative themes were identified using a grounded theory approach.

## RESULTS:

Overall, 48 studies were included, with 59 subjects for DC and 459 subjects for DR quantitative analysis. Both sexes were represented in the samples. The pooled prevalence of DC across 4 studies was 88% (95% CI: 58%-97%), and the pooled prevalence of DR was 10% (95% CI: 5%-18%), with a heterogeneity of  $I^2=0.78$ . Heterogeneity was not calculated for DC due to the limited number of included studies. Four major qualitative themes regarding amputation decision-making were identified: (1) the strongest motivating factors for amputation were to control pain, improve function, and improve quality of life, whereas social stigma was the main factor against amputation; (2) patient age, culture, and primary language affected patient attitudes regarding amputation; (3) long-term postoperative satisfaction is high, though there is an initial adjustment period with low satisfaction; (4) patients desire to be involved in the decision-making process.

## DISCUSSION:

Our study found that the prevalence of DC is high and DR is low among patients who had undergone amputation. Patient-reported factors contributing to DC included a lack of information, feeling uninvolved in care discussions, feeling that amputation was discussed too late in the disease course, or cultural beliefs opposed to amputation. These findings emphasize the importance of including patients early on in discussions regarding their care and providing high-quality information in a way that is understandable by patients. Moreover, amputation should not be introduced as a last resort treatment option or be perceived as a surgical failure by patients or surgeons. Rather, it is important to discuss amputation openly with patients and to tailor the decision to each individual patient's goals of care. A major limitation is the absence of validated DR scales in the included studies; our analysis was of study-specific questionnaires with high heterogeneity. Further prospective studies investigating rates of DC and DR using validated scales are warranted to better understand patients' decision-making processes regarding amputation.

## CLINICAL RELEVANCE:

Orthopaedic surgeons and patients often have difficulty engaging in discussions regarding amputation, yet the prevalence of phenomena relating to distress in the context of amputation decision-making has not been quantitatively studied. Our systematic review and meta-analysis preliminarily identified the prevalences of decisional conflict and decision regret and themes shared across studies regarding patient attitudes towards the decision-making process, and provides a starting point for identifying interventions for surgeons to use to ameliorate these negative affective experiences and to guide future research.

## IMAGES AND TABLES:

Forest plots of pooled prevalences of DC (left) and DR (right)

