



Financial Toxicity Associated with Cleft Palate Repair: A Survey of Family Financial Well-Being

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Introduction

Financial toxicity refers to the economic burden of treatment on patients, families, and caregivers of those with chronic medical conditions. Previous studies have assessed the costs associated with treatment of a child with cleft palate and found that the costs were similar to those of children with chronic illness, like Down syndrome. We sought to use self-reported data to assess how cost of treatment impacts the financial wellbeing of families of children with cleft palate.

Methods

Using ICD codes to identify patients who underwent cleft palate reconstruction at Lurie Children’s Hospital, a list of 639 patients was collected from the electronic medical record. A survey that assessed income, debt, and other indicators of financial impact, such as out-of-pocket (OOP) costs, was sent to the parents of the patients. Descriptive and comparative statistics were calculated to assess the impact of the cost of care on families' financial standing.

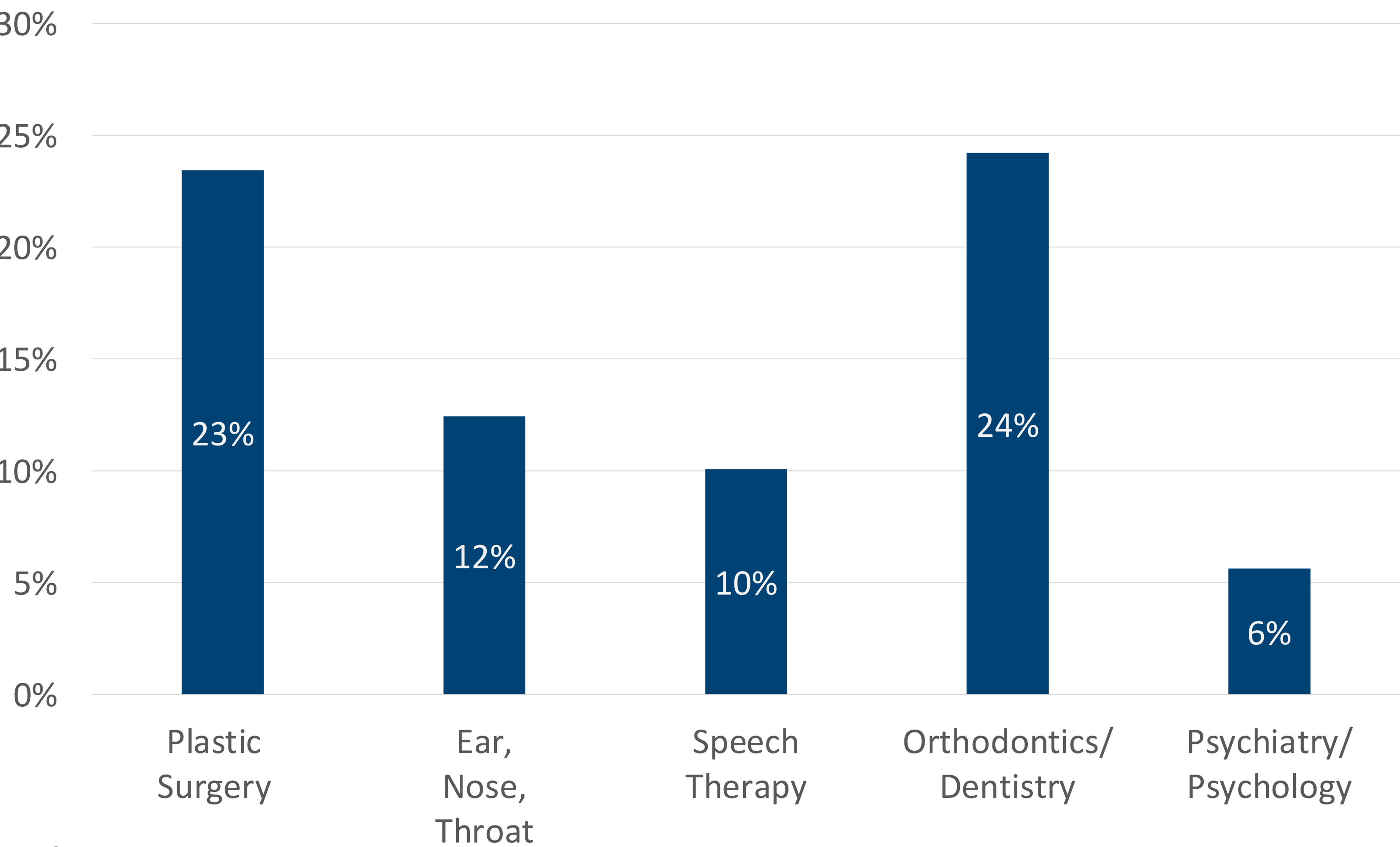


Figure 1. OOP Costs by Specialty

Results

There were 64 respondents (10%) who completed the survey in its entirety. The average total OOP cost to families was \$45,140 (range: \$0-\$400,000). Patients were asked to report their debt prior to their child’s surgery and their current debt. 11 families (17%) reported that their debt balance had increased, while only 3 families (5%) reported an improvement in their debt. However, there was no significant association between increased debt balance and total OOP costs, both within the first two years of treatment after surgery and in total (p=0.40, p=0.86 respectively). The average orthodontic/dentistry OOP costs for those who decreased their debt balance was \$3,286 compared to \$16,372 for those who maintained the same or had an increased debt balance. However, due to the variability of the data, these were not significant (p=0.54). The specialties that patients reported that most of their OOP costs went to were plastic surgery (23%) and orthodontics/dentistry (24%). 39 respondents (61%) reported that they did not reduce or had a minor reduction in their working hours, while 25 respondents (39%) reported a moderate to complete reduction in their working hours. Furthermore, 18 respondents (28%) reported that their spouse also lost income due to caring for their child during treatment. Over half of respondents (53%) reported that they and their partner missed more than 3 weeks of work cumulatively throughout their child’s treatment. 30 respondents (47%) reported a reduction in essential household expenses and 40 respondents (63%) reported a reduction in non-essential spending.

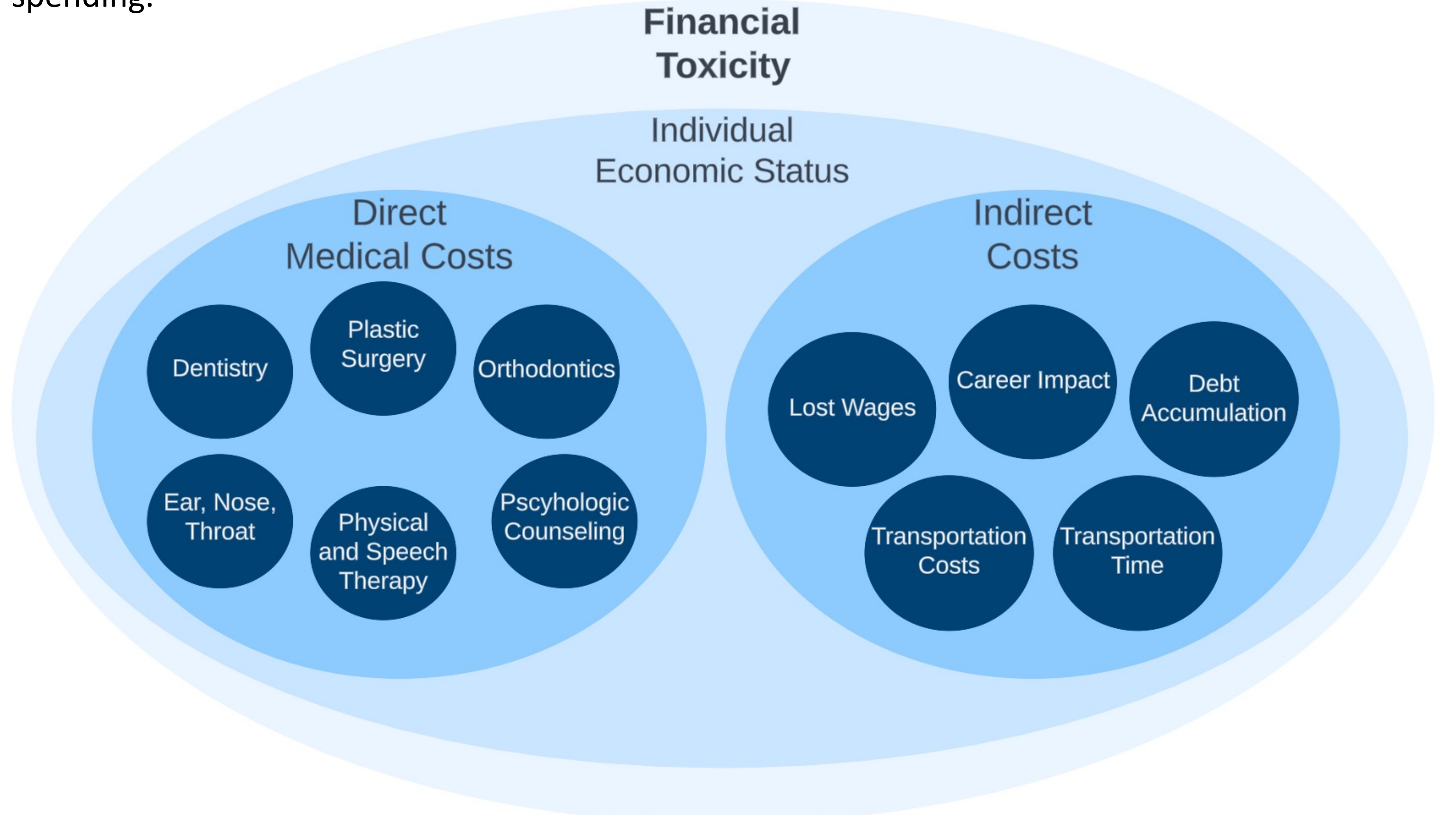


Figure 2. Factors Influencing Financial Toxicity

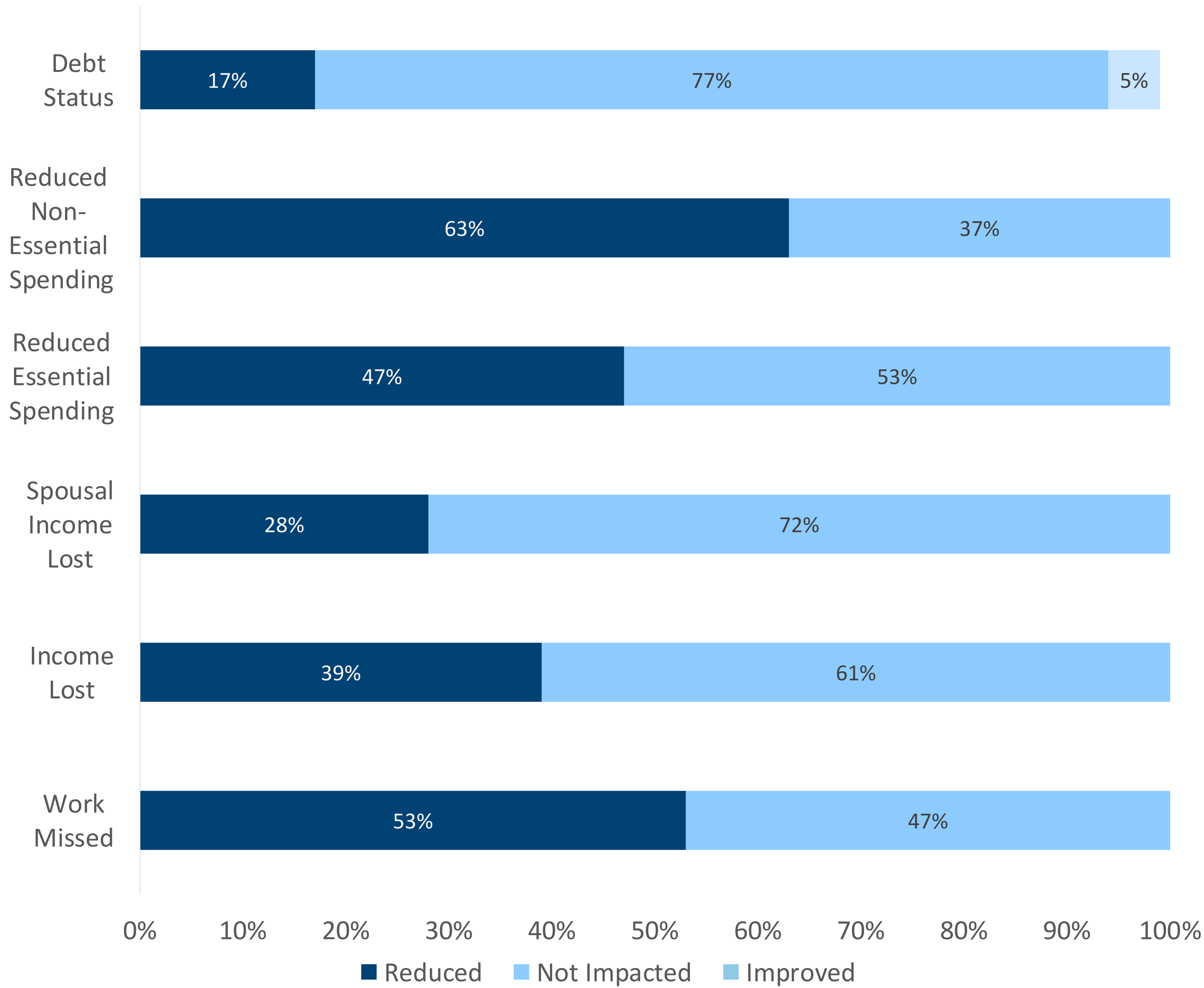


Figure 3. Indirect Costs of Cleft Palate Repair

Conclusion

The burden of cleft palate care has a malignant effect on families’ financial standing. Further studies will need to elucidate how these variables are affected in patients who do not have a child with cleft palate. Additionally, legislation currently being developed, including the Ensuring Lasting Smiles Act, will serve to provide better coverage for patients undergoing cleft palate repair; especially considering that OOP costs were most often associated with orthodontics and dentistry, the ELSA act will ameliorate these exuberant costs and therefore the financial burden of treatment for these patients and their families.