Evaluating Dental Educational Materials Needs for the Lowe Syndrome Community



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Introduction

Lowe syndrome (LS) is a rare X-linked recessive disorder caused by a mutation of the OCRL1 gene, localized to Xq24q26. Children with LS present with abnormalities of the eyes, renal system dysfunction including proteinuria, psychomotor impairment leading to delayed and intellectual development. Despite limited research as evident in Figure 1, studies have found that these individuals experience increased dental problems including enamel hypoplasia, enlarged pulp chambers, hematomas, tooth mobility, caries, and taurodontism.



Such dental problems have made extractions and other invasive procedures prevalent in this population causing behavioral issues during office visits. 15% of parents/guardians have reported difficulties in accessing care, urging for an increase in awareness, research, and overall improvement for the oral health of LS patients.

Objective

This study aimed to assess dentists' experience with treating individuals with LS, explore limitations to providing care for these individuals, and identify the gaps in knowledge regarding care for individuals with special needs. Additionally, we aimed to analyze perceptions of the need for educational materials tailored to the LS community about the dental setting. These insights serve as a guide to target specific areas for future interventions to improve oral health care for this population.

A 28-question survey was developed using Qualtrics and pre-tested for face and content validity. Table 2 below breaks down the content of the survey questions. A fivepoint Likert scale was used as the predominant form for questions where subjects selected an answer ranging from strongly agree to strongly disagree. A link to the survey was emailed to the listserv of the TUSDM alumni. The survey was active from September 26, 2023, to December 12, 2023. Data were analyzed using the chi-square test for statistical significance for binary outcomes. The significance level was set at α =.05. SPSS v. 28 (IBM Corp., Armonk, NY, USA) was used for the analysis.

Methods

Table 2. Qualtrics Survey Details		
Demographics	Dental Experience	Perceptions
Total: 5 questions Ethnicity Race Age Location of practice Specialty (if applicable)	Total: 14 questions Years of experience # of patients seen per day/week Work/exposure to special needs patients Oral findings of patients with LS Behavioral observations of patients with LS	Total: 9 questions - Likert scale questions regarding the need for educational materials for patients with LS Select all that apply questions regarding type of materials and perceptions on features of materials
I consent question - If subject selected "No", survey was concluded question regarding location of subject at time of survey - If subject was outside of the United States, survey was concluded		

Results

Data from six subjects were not included in the statistical analysis as they did not meet the inclusion criteria. Thus, a sample size of n=73 was achieved. As some of these subjects provided responses to only some items, sample sizes varied across the different survey items. Figure 2 depicts the specialties of subjects while the pie chart (Figure 5) shows the levels of agreement on the need for educational materials for LS patients. Figure 3 illustrates the perceptions towards the different types of materials as introductory dental videos were deemed most helpful.



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Figure 4 compares dentists and specialists from the subject pool and their reasons for not being able to treat a person with LS. Not having experience treating special needs children only had statistically significant value (p=0.022) between the groups; the rest were not significant.

Conclusion

This research complements a previous study that identified the importance of access to dental care for this community. thereby providing a fuller picture of the substantial barriers to dental care faced by individuals with LS. Overall, our results conclude that educational materials for the dental setting as mentioned above should be developed for the LS community. Future research could focus on developing and testing the efficacy of these materials. Lastly, our study highlights a systemic issue; the need for dental schools to place a greater emphasis on special care in dentistry as inexperience is one of the most common barriers to care.