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Association of Social Determinants of Health with Time to Diagnosis and Treatment Outcomes in Idiopathic Subglottic Stenosis

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Abstract

Objectives: To examine whether social determinants of health (SDH) factors are associated with time to diagnosis, treatment selection, and time to recurrent surgical intervention in idiopathic subglottic stenosis (iSGS) patients.

Methods: Adult patients with diagnosed iSGS were recruited prospectively (2015–2017) via clinical providers as part of the North American Airway Collaborative (NoAAC) and via an online iSGS support community on Facebook. Patient-specific SDH factors included highest educational attainment (self-reported), median household income (matched from home zip code via U.S. Census data), and number of close friends (self-reported) as a measure of social support. Main outcomes of interest were time to disease diagnosis (years from symptom onset), treatment selection (endoscopic dilation [ED] vs. cricotracheal resection [CTR] vs. endoscopic resection with adjuvant medical therapy [ERMT]), and time to recurrent surgical intervention (number of days from initial surgical procedure) as a surrogate for disease recurrence.

Results: The total 810 participants were 98.5% female, 97.2% Caucasian, and had a median age of 50 years (IQR, 43–58). The cohort had a median household income of $62,307 (IQR, $50,345-$79,773), a median of 7 close friends (IQR, 4–10), and 64.7% of patients completed college or graduate school. Education, income, and number of friends were not associated with time to diagnosis via multivariable linear regression modeling. Univariable multinominal logistic regression demonstrated an association between education and income for selecting ED vs. ERMT, but no associations were noted for CTR. No associations were noted for time to recurrent surgical procedure via Kaplan Meier modeling and Cox proportional hazards regression.

Conclusions: Patient education, income, and social support were not associated with time to diagnosis or time to disease recurrence. This suggests additional patient, procedure, or disease-specific factors contribute to the observed variations in iSGS surgical outcomes.

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Keywords

income; education; social support; iSGS; diagnosis time; surgical outcomes

INTRODUCTION

Idiopathic Subglottic Stenosis (iSGS) is a rare fibroinflammatory disease that primarily affects healthy adult Caucasian women. Progressive endoluminal scarring in the proximal airway creates physiologic ventilatory impairment and life-threatening dyspnea.[1–3] Multiple types of surgical and medical therapies are employed to manage iSGS with varying efficacy and impact on quality of life. Previous work has demonstrated differences in effectiveness of the three major surgical treatment approaches: Endoscopic dilation (ED), Cricotracheal resection (CTR), and Endoscopic resection with adjuvant medical therapy (ERMT).[4,5] Despite treatment, a large proportion of affected individuals require repeat surgical interventions for airway management, with the highest being those treated by ED.[3–5] Prior reports could not attribute these differences in surgical effectiveness to variations in disease severity (i.e., using standard anatomic staging criteria, number of prior procedures, or time to diagnosis).[5] One unexplored influence are the Social Determinants of Health (SDH).[6]

SDH factors are distinct from race and ethnicity and are categorized into five overlapping domains of: 1) economic stability, 2) education, 3) social support, 4) access to health services, and 5) community context.[6,7] These environmental and structural factors can significantly impact population health, with substantial evidence linking SDH to health outcomes and quality of life in numerous conditions, including infectious, cardiovascular, endocrine disease, and chronic rhinosinusitis care.[7–13] Previous work has demonstrated the association of SDH on surgical outcomes in post-intubation laryngotracheal stenosis.[14] To date, no study has investigated the effects of SDH on iSGS clinical outcomes.

The iSGS population represents a unique opportunity to evaluate the role of SDH factors on patient outcomes. The highly consistent patient characteristics (98% female and 97% Caucasian) limit confounding due to race and/or ethnicity. This study examines the association of SDH factors (economic stability, education and social support), on time to diagnosis, treatment selection, and time to disease recurrence.

MATERIALS AND METHODS

The study was approved by Vanderbilt University Medical Center Institutional Review Board and utilized data from the iSGS[1000] patient cohort[3–5] (a prospective cohort of 1000 iSGS patients established in 2014 by the North American Airway Collaborative [NoAAC]) housed within the NoAAC data coordinating center. The NoAAC-11[5] was designed by three fellowship-trained laryngologists and implemented with extensive input from a patient advocate (administrator of the “Living with iSGS” Facebook group).

Participants:

Adults patients (>18 years of age) experiencing obstructing subglottic stenosis that could not be attributed to intubation-related airway trauma or medium-vessel vasculitis were recruited.[5] Additional exclusion criteria are previously described.[5] Enrolled patients were consented, and provided demographical information, including age, sex, race/ethnicity, and zip code of primary residence, as well as self-reporting their highest level of education attained and number of close friends.

Internet Utilization:

All participants were given a baseline NoAAC-11 survey, which was used as a proxy for internet utilization preceding disease diagnosis.[5] The survey queried patient demographics, clinical characteristics, treatment history and decision-making process, and level or type of online social media engagement. The survey was administered to the iSGS[1000] patient cohort electronically via a secure and information-protected REDCap form (Nashville, Tennessee) for 45 days in January-February 2018.

Socioeconomic Data:

Three categories of SDH were examined: 1) highest level of educational attainment (self-reported by participants; categorical: graduate school, college graduate, some college, high school or less); 2) median household income (determined from 5-digit home zip codes using the 2017 American Community Survey 5-year estimates[15]; continuous); and 3) social support, using self-reported number of close friends[16,17] (contained in an administered Medical Outcomes Study [MOS] Social Support Survey[18,19]; continuous). Only U.S. patients were included for income analysis, due to reliable availability of household income data as provided by the U.S. Census Bureau.[15] Median household income was grouped into quartiles based on distribution of patients, as was number of close friends.

Clinical Outcomes:

Three primary outcomes were evaluated: 1) Time to disease diagnosis (defined as the number of years from the date of first symptom to date of disease diagnosis); 2) Treatment Selection (of ED vs. ERMT vs. CTR); and 3) Treatment Outcomes, measured using time to recurrent surgical intervention (defined as the number of days from initial surgical procedure to recurrent surgery). Time to recurrent surgical intervention was used as a surrogate for disease recurrence, and was examined in ED and ERMT-treated patients independently (given the sufficient number of patients to power statistical analysis, N=603 and N=121, and to remove the published treatment effect).[4] In CTR-treated patients, with low rates of recurrent procedures, the Clinical COPD Questioneer (CCQ) Dyspnea Index at 1 year post-enrollment was instead utilized, to assess subjective post-operative patient-reported breathing outcomes.

Statistical Analysis:

Multivariable linear regression was used to evaluate the association of each SDH factor (income, education, number of close friends) on Time to Diagnosis, adjusting for patient age, time spent on social media, and treatment type. For treatment selection (between

ED, CTR, ERMT), univariable multinomial logistic regression was used. For treatment outcomes, Kaplan-Meier estimates and Cox proportional hazards regression analysis were used to evaluate time to recurrent surgical intervention. In CTR-treated patients, univariable linear regression was used between each SDH factor and the CCQ Dyspnea Index. All analysis used categorical groups for education, quartiles for income, and quartiles for number of friends. All testing was two-sided, and p-values ≤ 0.05 were considered statistically significant. Analysis was performed using Stata 16 (StataCorp, College Station, TX), GrapPad Prism 8.3 (GraphPad Software, La Jolla, CA), and R version 3.6 (R Foundation for Statistical Computing, Vienna, Austria).

RESULTS

Study Population

In total, 1056 patients were consented as part of the NoAAC study. After excluding patients without a confirmed index operative date or incomplete baseline surveys, 810 patients met inclusion criteria. Of this cohort, 798 patients were female (98.5%), 787 were Caucasian (97.2%), and median age was 50 years (IQR: 43–58 years). For SDH analysis, 752 patients (92.8%) self-reported their highest educational level; 657 patients (81.1%) had available median household incomes (after excluding non-U.S. patients and those without recorded home zip codes); and 637 patients (78.6%) self-reported number of close friends. These participants in total had a median of 7 close friends (IQR: 4–10; range: 0–51). Median household income of the included patients (N=657) was $62,307 (IQR: $50,345– $79,773; range: $28,476–$180,962), which is comparable to the national U.S. median income for Caucasian households of $65,273 (margin of error: +/− 685).[20] Additional patient characteristics are listed in Table 1.

SDH Factors and Time to Diagnosis

Overall, among all iSGS cohort patients with complete diagnostic information (N=578), median time to diagnosis was 1.58 years (IQR: 0.7–3.9). This did not significantly differ between the 3 treatment groups: ED=1.50 (IQR: 0.7–3.6), ERMT=2.08 (IQR: 0.7–5.8), CTR= 2.08 (IQR: 0.6–5.1). Multivariable regression analysis found no associations between time to diagnosis and patient income (effect size: −0.43; 95% CI: −1.25 to 0.38), education (effect size: −1.93; 95% CI: −4.78 to 0.93), or number of close friends (effect size: −0.08; 95% CI: −0.50 to 0.34). The only assessed variable that correlated with time to diagnosis was patient age, in which older patients tended to have a longer interval between onset of symptoms and diagnostic confirmation (Quartile 3 [Q3] vs. Quartile 1 [Q1]: effect size: 1.37, 95% CI: 0.39 to 2.34) (Figure 1).

SDH Factors and Treatment Selection

In univariable analysis of SDH factors to treatment groups, higher patient income was demonstrated to favor ED over ERMT (Q3 vs. Q1: OR=1.648; 95% CI: 1.50–1.81), as was higher education (college graduate or higher vs. below: OR=1.511; 95% CI: 1.01–2.28). No associations were seen with number of close friends (ED vs. CTR: 95% CI: 0.87–1.21; ED vs. ERMT: 95% CI: 0.85–1.06), or any SDH variable to the selection of CTR as treatment (eFigure 1).

SDH Factors and Treatment Outcomes

Within the ED treatment group (N=604), Kaplan-Meier analysis demonstrated no differences in the rate of recurrent surgical intervention due to income (Figure 2; N=478), education (Figure 3; N=559), or number of close friends (Figure 4; N=491). Similarly, in the ERMT-treated patients (N=121), no associations were seen for income (eFigure 1; N=110) or education (eFigure 2; N=113). However, there was an inverse relationship between the number of close friends and the probability of recurrent procedure after ERMT, with hazard ratio (HR)=9.031 (95% CI: 2.07–76.29; eFigure 3; N=83). In CTR-treated patients, patient CCQ scores at 1-year post-enrollment had no significant associations with income, education, or number of close friends (eTable 1).

DISCUSSION

Idiopathic Subglottic Stenosis is a rare, recurrent, fibroinflammatory disorder that results in physiologic ventilatory impairment in adult Caucasian women. While ongoing work continues to investigate the genetic risks and disordered host immunity in disease initiation and progression, the observed variability in surgical outcomes and disease recurrence remain to date unexplained. This study is the first to investigate the role of social determinants of health in diagnostic and treatment outcomes of iSGS, focusing on income level, education, and social support as measured by number of close friends. Our results showed no associations between income or education to time to diagnosis or time to recurrent surgical procedure, but they did show some correlation with treatment selection. Number of close friends did not demonstrate an association with any of the assessed outcomes.

SDH Factors and Time to Diagnosis

Unsurprisingly, one of the central challenges for all rare diseases is the initial diagnosis.[21,22] Patients with rare diseases are delayed an average of 6 years after symptoms onset and see an average of 7.3 physicians prior to receiving an accurate diagnosis.[22,23] Diagnostic delays significantly impact quality of life in patients with rare diseases, and misdiagnosis and incorrect treatments also frequently and substantially increase costs for individual patients and overall healthcare systems.[23,24] They are believed to be partly driven by insufficient knowledge and lack of awareness, particularly in primary care settings.[25] Low disease incidence in combination with numerous possibilities of rare conditions almost inevitably leads to inadequate understanding and delayed recognition.[26] In particular, lack of condition-specific understanding can contribute to diagnostic errors and false verifications when alternative diagnoses are not taken into consideration after a first initial diagnosis.[25] This phenomenon, known as premature closure, is reported to be among the most common single types of error in medicine.[25]

These concepts are applicable to iSGS patients whose disease is not widely recognized in primary care settings. Our analysis of SDH factors did not demonstrate an association between education, income, or social support to time to diagnosis – this was unexpected. Typically, higher education and income levels tend to correlate with better access to care, which often lead to earlier diagnoses.[7,8] Interestingly, the delay in iSGS diagnosis was shorter than that published for other rare diseases (median of 1.58 years vs. median of

6 years).[22] This comparatively shortened interval may be due to the severe nature of physiologic impairment afforded by iSGS symptoms.

SDH Factors and Treatment Selection

Our results showed a preference for patients with higher household incomes and higher education levels to select ED for treatment. In considering these results, it is worth noting that most healthcare facilities in the U.S. do not typically offer all three types of surgical interventions for iSGS. Geographic proximity to a hospital could be a primary reason for patients to receive a particular treatment, with education and incomes levels of that vicinity as intermediate associations. The association of SDH with treatment selection is therefore difficult to disentangle from the socioeconomic status of the neighborhoods in close proximity to available treatment centers.

SDH Factors and Surgical Outcomes

Investigation of clinical factors affecting treatment outcomes in post-intubation laryngotracheal stenosis (iLTS) demonstrated an association between low SDH and long-term tracheostomy dependence after open reconstruction.[14] The present study did not find any differences in time to recurrent surgical procedure due to income or education. However, the patient characteristics and clinical outcomes of a localized fibroinflammatory disorder follow very different trajectories than those of critical illness. One of the major ways in which SDH factors affect disease outcomes is by influencing patient comorbidities and baseline health.[8–12] With the majority of iSGS patients being otherwise healthy adults with low Charleston Comorbidity Index scores[3,4], their baseline health may offer a reserve against the typical influences of low education or economic instability.

Limitations

While SDH does not include race or ethnicity within its categorizations, both the World Health Organization and Centers for Disease Control and Prevention have demonstrated important interrelationships between them.[6–8] Specifically, Black and Latino patient populations have worse access to healthcare and poorer treatment outcomes when compared to White patients across a number of diverse diseases.[6–10] Given the homogeneity of the iSGS[1000] cohort (97–100% Caucasian),[3,5] it was not possible to adequately power comparisons between race subgroups. Despite this limitation (or perhaps because of it), the iSGS population offered a controlled patient sample to evaluate SDH factors in the absence of confounding due to racial or ethnic differences. It is also possible that other unmeasured covariates may have obscured a small but real influence of SDH on treatment outcomes. Given the observational nature of our study design, confounding due to unmeasured covariates cannot be fully accounted for and remains a limitation.

Additionally, while our results demonstrated a shorter diagnostic interval for iSGS than other rare diseases, there is potential for this to be influenced by recall bias, given the self-reported nature of this data collection process. Patient proximity to a tertiary care center could also influence the time to diagnosis. However, the study cohort included patients from regional practices as well as tertiary care referral centers, which helps to mitigate against a theoretically shorter diagnostic interval for higher-volume tertiary care centers.

In total, our results suggest yet unexplained factors may affect the delay in diagnosis and observed variations in disease recurrence.[4] These may include variations in surgical technique for a particular treatment approach (i.e. between centers primarily utilizing ED), environmental differences between treatment centers, and other disease or patient specific characteristics. Qualitative research with iSGS patients is ongoing and may help uncover additional explanations. Additional SDH factors not considered in this study were access to care, heath literacy, post-operative care regimens, nutrition, and patient personality traits,[6–8,29] which could be examined in future studies in relation to iSGS diagnostic and treatment outcomes.

CONCLUSIONS

The social determinants of health factors of income, education, and social support are not associated with time to diagnosis or time to recurrent surgical intervention in idiopathic subglottic stenosis. Our results reinforce the need for continued study of additional patient variabilities, such as procedural variation between surgeons, patient genetics, or disease characteristics that may impact treatment outcomes in iSGS.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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KEY POINTS

Question:

How are the social determinants of health related to time to diagnosis, treatment selection and time to recurrent surgical intervention in idiopathic subglottic stenosis?

Findings:

In this prospective study of 810 adults with iSGS, patient education, household income, and social support were not associated with time to diagnosis or time to recurrent surgical intervention. Differences in education and income levels were observed for different surgical treatment approaches.

Meaning:

Social determinants of health are not associated with time to diagnosis or treatment outcomes in iSGS but may impact treatment selection.

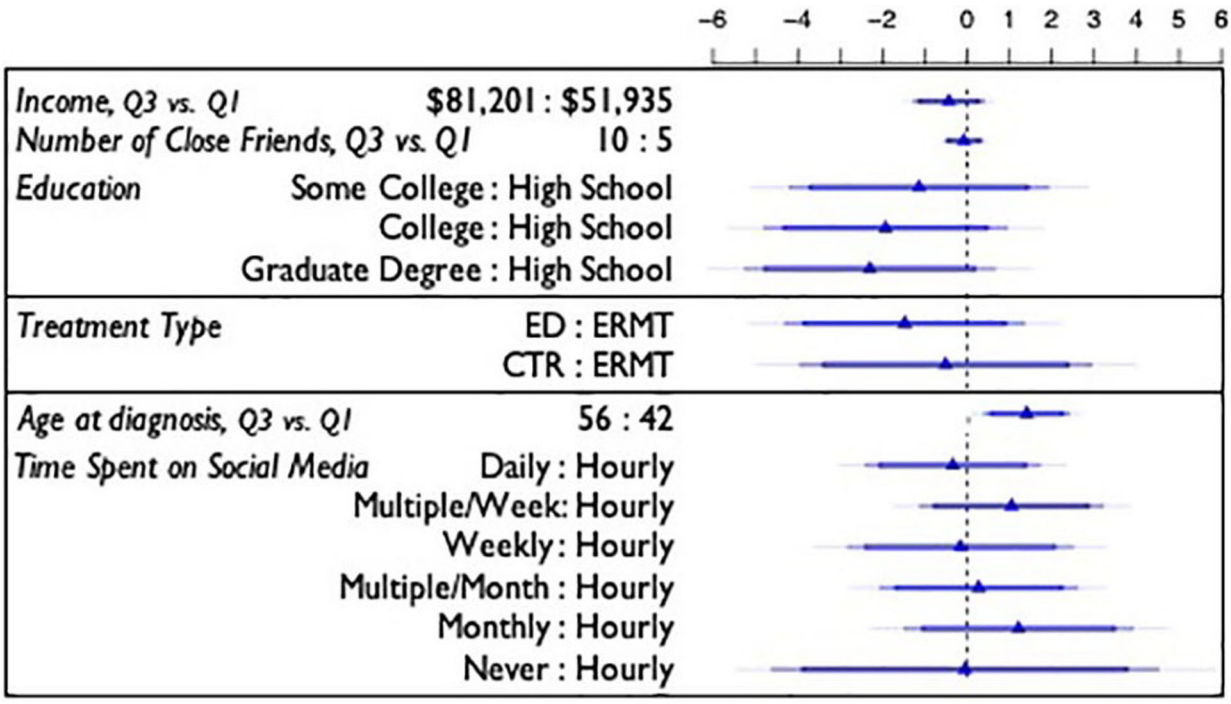

Figure 1.

Association of SDH factors and Time to Diagnosis. Multivariable linear regression of income, education, and social support to time to diagnosis (in patients with available data, N=578), controlling for patient age, time spent on social media, and treatment type. Triangles represent effect size, and bars represent 95% confidence intervals. Q1: first quartile; Q3: third quartile.

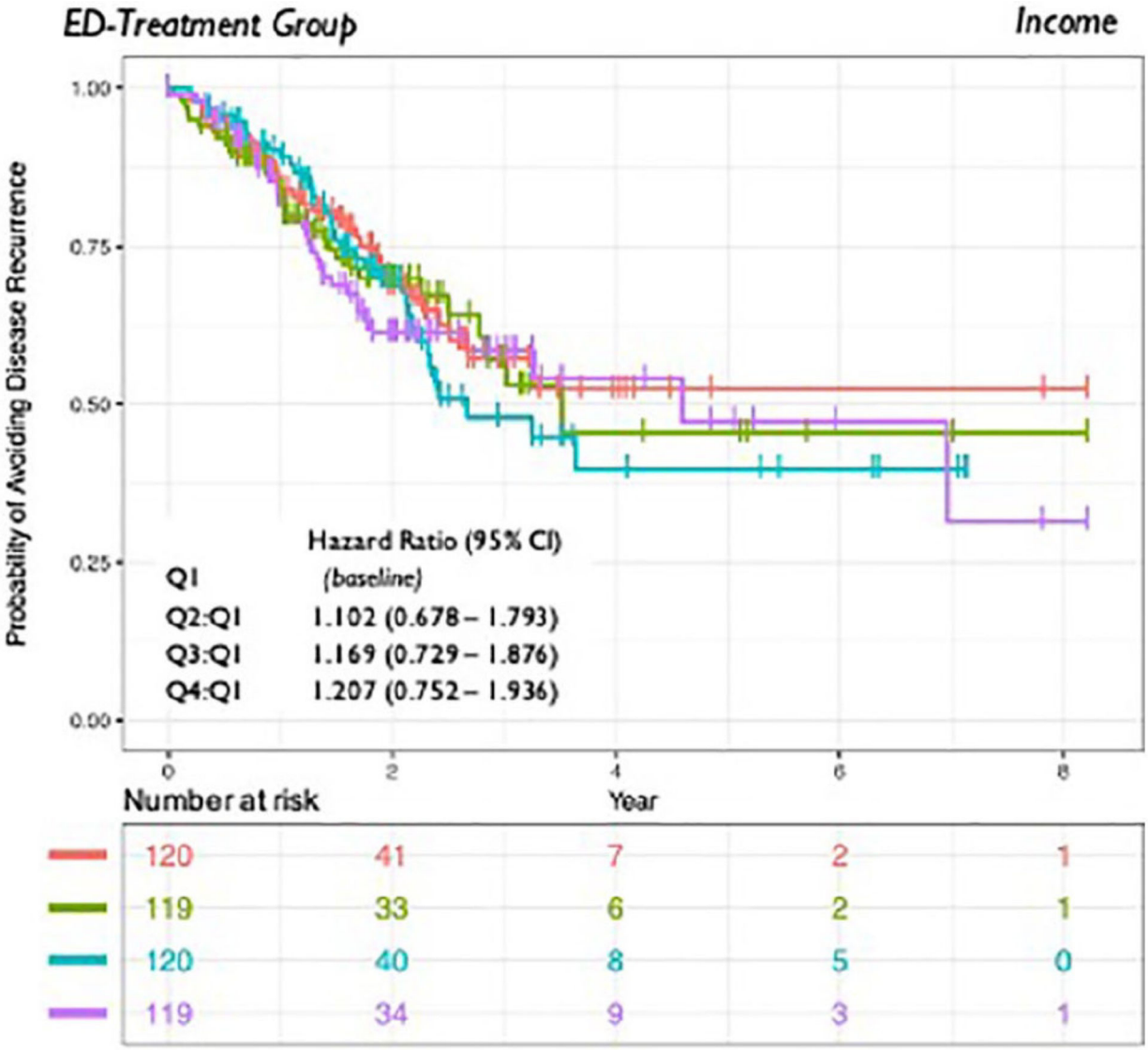

Figure 2.

Kaplan-Meier analysis of Median Household Income on time to recurrent surgical procedure in ED-treatment group. Percentage of patients avoiding recurrent procedures are stratified by income quartiles.

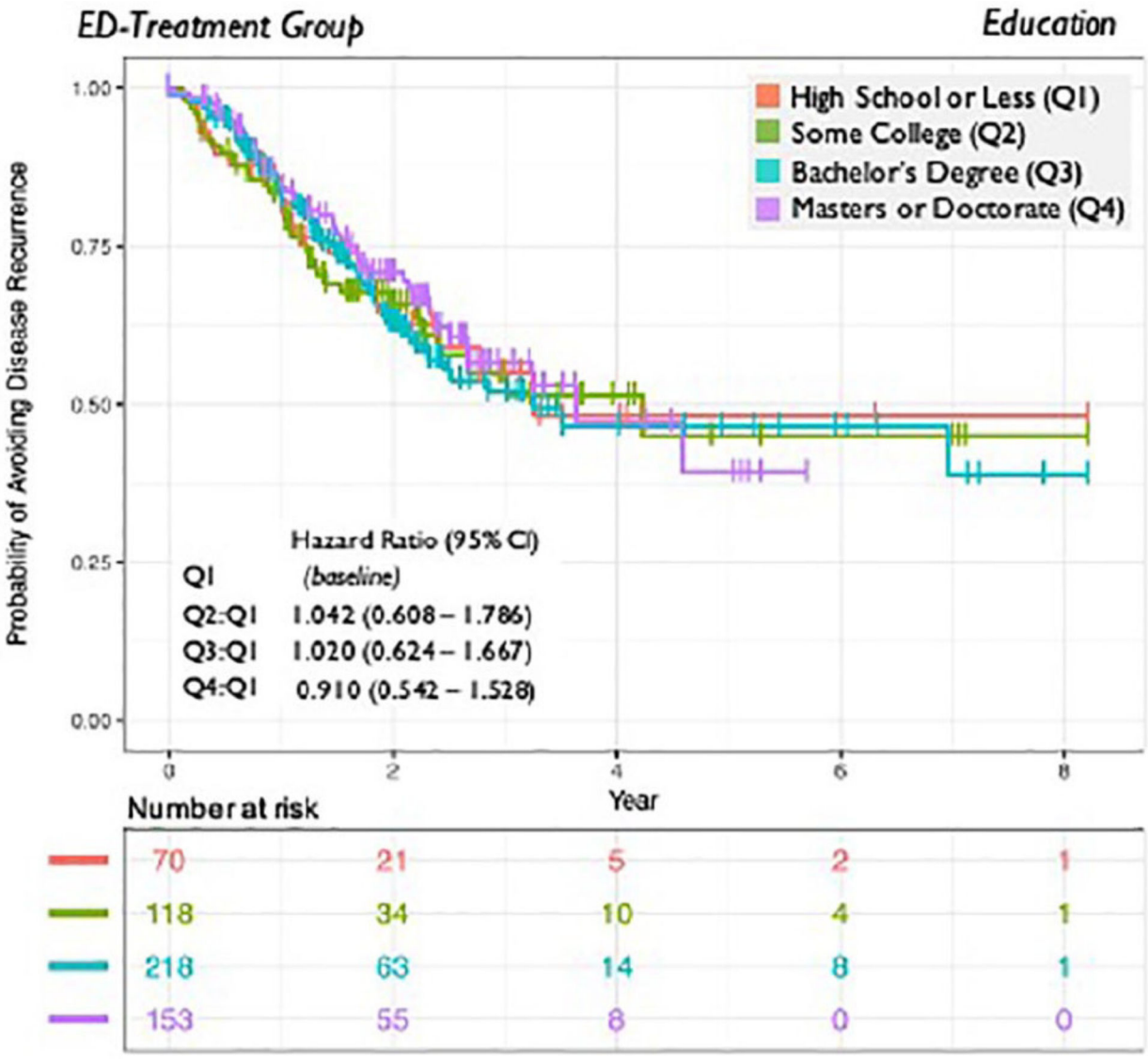

Figure 3.

Kaplan-Meier analysis of patient education on time to recurrent surgical procedure in ED-treatment group. Percentage of patients avoiding recurrent procedures are categorized by highest level of education.

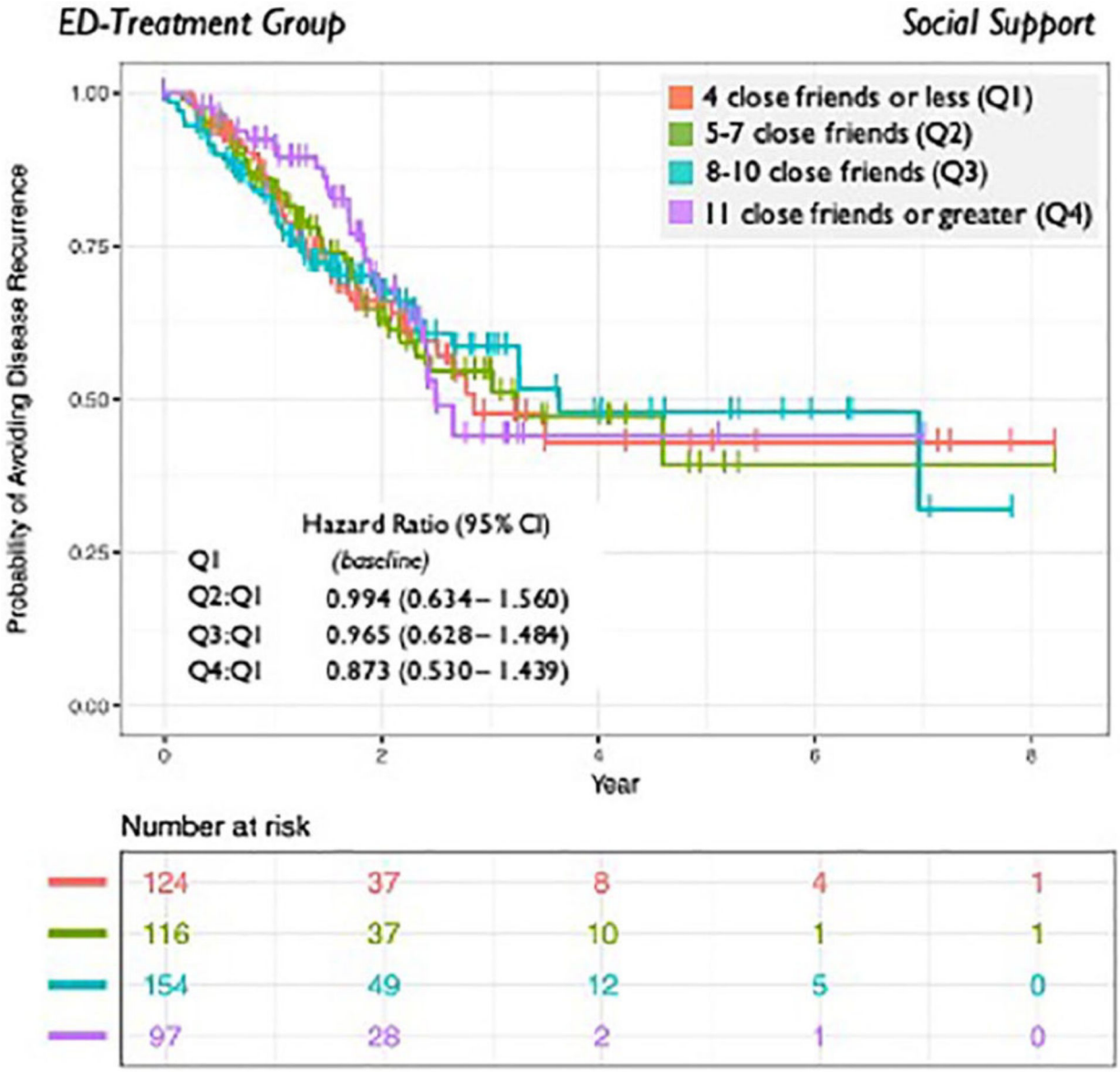

Figure 4.

Kaplan-Meier analysis of social support on time to recurrent surgical procedure in ED-treatment group. Percentage of patients avoiding recurrent procedures are stratified by quartiles of number of close friends.

Table 1.

Patient Demographics and Social Determinants of Health among iSGS Patients.

	All patients N = 810	ED (N = 603)	CTR (N = 86)	ERMT (N = 121)
Demographics				
Age[a], median years (IQR)	50 (43–58)	49 (42–57)	48 (39–55)	56 (48–63)
Time to diagnosis, median years (IQR)	1.58 (0.7–3.9)	1.50 (0.7–3.6)	2.08 (0.6–5.1)	2.08 (0.7–5.8)
Sex, *N* female (%)	798 (98.5)	593 (98.3)	84 (97.5)	121 (100)
White (non-Hispanic), *N* (%)	787 (97.2)	580 (95.9)	86 (100)	121 (100)
Marital Status, *N* married (%)	582 (77.2)	426 (76.1)	70 (86.4)	86 (76.1)
Total procedures, *N* (range)	3 (2–7)	3 (2–7)	5 (3–7)	3 (2–6)
Social Determinants of Health				
Highest Education Level, *N* (%)				
Graduate school	189 (25.1%)	153 (27.4%)	14 (17.5%)	22 (19.5%)
College Graduate	298 (39.6%)	218 (39.0%)	38 (47.5%)	42 (37.2%)
Some college	175 (23.3%)	118 (21.1%)	23 (28.7%)	34 (30.1%)
High school or less	90 (12.0%)	70 (12.5%)	5 (6.2%)	15 (13.3%)
Median Household Income[b], USD (IQR)	62,307 (50,345 – 79,773)	65,291 (50,758 – 82,291)	56,084 (47,931 – 82,143)	57,944 (50,273 – 67,083)
Close friends, median *N* (IQR)	7 (4 –10)	7 (4 –10)	6 (5 –10)	10 (5 –12)

[a] Age represents patient age at index procedure.

[b] Median Household Income was evaluated for U.S. patients only (N=657).

Abbreviations: CTR: cricotracheal resection; ED: endoscopic dilation; ERMT: endoscopic resection with adjuvant medical therapy; IQR: interquartile range.