

Financial burden is associated with worse health-related quality of life in adults with multiple endocrine neoplasia type 1

Benjamin J. Peipert, BA,^a Sneha Goswami, BA,^a Irene Helenowski, PhD,^a Susan E. Yount, PhD,^b and Cord Sturgeon, MD, MS,^a Chicago, IL

Background. Health-related quality of life and financial burden among patients with multiple endocrine neoplasia type 1 is poorly described. It is not known how financial burden influences health-related quality of life in this population. We hypothesized that the financial burden attributable to multiple endocrine neoplasia type 1 is associated with worse health-related quality of life.

Methods. United States adults (≥ 18 years) with multiple endocrine neoplasia type 1 were recruited from the AMENSupport MEN online support group. Patient demographics, clinical characteristics, and financial burden were assessed via an online survey. The instrument Patient-Reported Outcomes Measurement Information System 29-item profile measure was used to assess health-related quality of life. Multivariable linear regression was used to identify significant variables in each Patient-Reported Outcomes Measurement Information System domain.

Results. Out of 1,378 members in AMENSupport, our survey link was accessed 449 times (33%). Of 153 US respondents who completed our survey, 84% reported financial burden attributable to multiple endocrine neoplasia type 1. The degree of financial burden had a linear relationship with worse health-related quality of life across all Patient-Reported Outcomes Measurement Information System domains ($r = 0.36-0.55$, $P < .001$); 63% reported experiencing ≥ 1 negative financial event(s). Borrowing money from friends/family (30%), unemployment (13%), and spending $> \$100$ /month out-of-pocket on prescription medications (46%) were associated consistently with impaired health-related quality of life ($\beta = 3.75-6.77$, $P < .05$). Respondents were 3- and 34-times more likely to be unemployed and declare bankruptcy than the US population, respectively.

Conclusion. This study characterizes the financial burden in patients with multiple endocrine neoplasia type 1. Individuals with multiple endocrine neoplasia type 1 report a high degree of financial burden, negative financial events, and unemployment. Each of these factors was associated with worse health-related quality of life. (Surgery 2017;■■■■.)

From the Departments of Surgery^a and Medical Social Sciences,^b Northwestern University Feinberg School of Medicine, Chicago, IL

MULTIPLE ENDOCRINE NEOPLASIA TYPE 1 (MEN1) is a rare, autosomal dominant, hereditary cancer syndrome characterized by neoplasms of the parathyroid glands, pancreas, and pituitary gland, as well as other endocrine and nonendocrine tissues.¹ A

high degree of financial burden has been documented among cancer patients,² including patients seeking treatment for neuroendocrine tumors.³ Cancer is one of the most costly medical conditions with high out-of-pocket costs even years

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Reprint requests: Cord Sturgeon, MD, MS, 676 North Saint Clair Street, Suite 650, Chicago, IL 60611. E-mail: cord.sturgeon@nm.org.

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after initial diagnosis.^{2,4,5} Cancer patients and survivors are more likely to be unemployed or miss work due to complications of their medical condition and treatment,⁴⁻⁶ and levels of debt and bankruptcy are out of proportion relative to the general population.^{7,8} This high level of financial burden has been associated with a high level of stress and anxiety, as well as worse physical and mental health-related quality of life (HRQOL) among cancer patients and cancer survivors.^{9,10}

Patient-reported outcome (PRO) measures regarding HRQOL can inform researchers and health care providers about the experience of individuals living with MEN1. The patient-reported outcome measures may help gauge the burden of disease and indicate those factors associated with impaired HRQOL. Neither HRQOL nor financial burden has been well characterized in patients with MEN1,^{11,12} and the extent to which financial burden affects HRQOL in this disease is not known.

We surveyed a group of adults with MEN1 to assess the extent of financial burden and its relationship to HRQOL in this population. We hypothesized that (1) adults with MEN1 would have a high degree of financial burden attributable to their illness and treatments, and (2) financial burden attributable to MEN1 would be associated with worse HRQOL outcomes.

METHODS

Survey design. We designed a 2-part hypothesis-driven survey in collaboration with members of AMENSupport, an international online support group for people living with MEN. The first portion of the survey collected information regarding participant eligibility, demographics, diagnosis, presentation, treatment, and financial burden associated with MEN1. This part of the questionnaire was vetted by a pilot group of 4 MEN1 patients and 4 clinicians with expertise in clinical research and survey design. Several tumor types, including pituitary adenomas, carcinoid tumors, adrenal tumors, and cutaneous manifestations of MEN1, were omitted from the survey based on feedback from patients in order to limit the number of questions and maximize participant response rate.

Elements of financial burden assessed included self-reported degree of burden, employment status, household size, annual income, cost of prescription medications, and number of negative financial events. Study participants were asked to rate the degree to which their physical condition or medical

treatment for MEN1 caused them financial difficulties. Responses were collected via a 4-point Likert scale ranging from “Not at all” to “Very much.” We included 6 different categories of negative financial events: (1) borrowing money from friends or relatives, (2) taking out new loans or a new mortgage, (3) using up most or all of one’s savings, (4) reaching one’s maximum credit card limit, (5) having been contacted by a collection agency, and (6) declaring bankruptcy. These questions were selected based on prior use in other studies that assessed financial burden in cancer populations^{4,9,10,13} and based on feedback from our pilot population of patients with MEN1.

The second portion of the survey assessed patient-reported HRQOL via the Patient-Reported Outcomes Measurement Information System (PROMIS) 29-item profile measure (PROMIS-29), which measures HRQOL across 7 domains (anxiety, depression, pain interference, fatigue, physical function, satisfaction with social role participation [ie, social function], and sleep disturbance) and one pain intensity item (rating pain intensity from 0 to 10).¹⁴⁻¹⁹ Responses were scored and converted to T-scores \pm standard deviation using the HealthMeasures Scoring service (www.healthmeasures.net). A value of 50 (standard deviation = 10) represents the mean score for each PROMIS domain in the general US population.²⁰ Higher scores in the domains of anxiety, depression, fatigue, pain interference, and sleep disturbance reflect worse HRQOL, while lower scores in physical function and social function reflect worse HRQOL.

Survey administration and data collection. Our survey instrument was composed and distributed via REDCap, a secure, Web-based application with the capability to construct and administer surveys for clinical research.²¹ All participants affirmed electronic consent prior to initiating the survey. After confirming study eligibility and obtaining participant consent, study participants were assigned automatically a unique identification number, which was stored within the REDCap database, enabling anonymous data collection. Participant consent and responses were stored in REDCap within the Center for Data Science and Informatics of Northwestern University. The survey was administered entirely online. No paper surveys or telephone surveys were administered. The study was approved by the Northwestern University Institutional Review Board prior to launch.

Subject recruitment. Participants were recruited online from AMENSupport ($n = 1,378$) via a public URL posted and promoted on the AMENSupport

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