

Assessing Quantitative and Qualitative Health Care Costs Associated with Marfan Syndrome

Jilliane Miller, Elizabeth DeChene, MaryAnn W. Campion, Maureen Flynn
Boston University School of Medicine, Boston, Massachusetts

Marfan syndrome is a chronic connective tissue disorder that affects multiple different systems within the body. While there is no cure for the syndrome, there are an array of prophylactic and screening options to prevent morbidity and mortality associated with Marfan syndrome. Since many of the major, multi-system issues involved with Marfan syndrome do not present as acute illness except in cases of aortic dissection, much of the recommended care may not be covered by an individual's health insurance. Additionally, individuals without, or with limited, insurance coverage may find that their monthly screening costs become prohibitive to seeking care, since screening recommendations can be prohibitively expensive and include multiple bills for the same visit. Individuals with other chronic conditions may also have similar costs and obstacles to recommended care. There is little literature that explores what costs individuals are facing and what health insurance is, and is not, covering. Additionally, the implications of health care costs on the feelings, perceptions, and life styles of individuals in the Marfan syndrome community have not been researched. Therefore, this study attempts to determine what costs the community is facing and how these costs affect the community and their actions regarding financial decisions and distribution. A questionnaire was created to investigate these factors both in individuals over 18 with Marfan syndrome and in parents of minors with Marfan syndrome. In our study we found that most individuals had insurance coverage of some kind and were pleased with the care they were receiving. However, the majority of individuals experienced increased health care costs despite insurance coverage. Our findings indicate that this leads to greater reports of stress, income redistribution, quality of life compromises and negative health and payment behaviors.