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Descripción de la calidad de vida y evaluación del nivel de conocimiento de un individuo con síndrome de Marfan sobre su enfermedad y el tipo de mutación que se presenta a nivel molecular

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Resumen
El síndrome de Marfan (SMF) es una enfermedad del sistema conectivo de tipo autosómica dominante de afección multiorgánica. Su buen pronóstico dependerá de un eficiente diagnóstico, tratamiento y al acoplamiento del paciente. El objetivo del proyecto se basa en la descripción de la calidad de vida y evaluación del nivel de conocimiento de un individuo con MFS sobre su enfermedad, sus manifestaciones, tratamientos y recomendaciones. Para ello se realizó un cuestionario, con puntos detallados, tales como: tiempo de diagnóstico, seguimiento por especialidades médicas, problemas de salud implicados por el síndrome, entre otras. Los resultados obtenidos en la encuesta muestran que el paciente, respecto a puntos generales de la enfermedad indicó como verdaderas 41% de las preguntas, un 27% de falsos, y no sabe o indica no tener conocimiento en un 32%, los cual indica un poco de vacío en cuanto a conocimiento. Conclusión: el conocimiento de SMF permite llevar una buena calidad de vida ya que hay una mejor adaptación al tratamiento recibido; lo cual mejora la resolución del cuadro a presentar.

Palabras Claves: Síndrome de Marfan, dilatación aortica, tratamiento y seguimiento,

Abstract

Marfan syndrome (MFS) is an autosomal dominant connective system disease of a multiorgan condition. the good prognosis will depend on an efficient diagnosis, treatment and coupling of the patient. The objective of the project is based on the description of the quality of life and evaluation of the level of knowledge of an individual with SFM about his disease, its manifestations, treatments and recommendations. To do this, a questionnaire was carried out, with detailed points, such as: diagnostic time, follow-up by medical specialties, health problems implicated by the syndrome, among others. The results obtained in the survey show that the patient, regarding general points of the disease indicated as true 41% of the questions, 27% false, and does not know or indicates not having knowledge in 32%, which indicates a bit of a vacuum in terms of knowledge. Conclusion: Knowledge of MFS allows a good quality of life, since there is a better adaptation to the treatment received, which improves the resolution of the table to be presented.

Keywords: Marfan syndrome, aortic dilation, treatment and follow-up

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