

# MARFAN SYNDROME AND COUNSELLING: A NEW PERSPECTIVE

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**Summary:** Marfan Syndrome is a connective tissue disorder, with autosomal dominant inheritance and a prevalence of 1/5000 individuals, caused by FBN1 mutations. The cardinal features of Marfan Syndrome involve the ocular, cardiovascular and skeletal systems. People with Marfan Syndrome are very complex patients with several health problems. Counselling is a helping profession that aims to facilitate processes of change, to reinforce evolutionary paths and to improve the quality of life, enhancing both resources and relationships surrounding environment through the relationship between practitioner and client (patient, family or group). The aim of our study is to evaluate the benefits of the Counselling in Marfan patients and familiars admitted in our Hospital.

**Materials and Methods:** this is an observational study about 100 people (Marfan patients and familiars) enrolled in our Marfan Syndrome Centre of Policlinico Tor Vergata with the collaboration of "Vittorio Association", a voluntary association taken care of Marfan patients and family. Monthly meetings were performed through the technique of **Artistic Counselling**. These meeting is called "**Olivia's Laboratories**". Different sessions have been organized from pure emphatic listening to more operative meetings

**Results:** The study showed that Counselling has a beneficial effect on Marfan patients and family members. Art therapy offers a safe and effective way to explore difficult life events and inner struggles. It can help to transform emotions and relationships and provide insight for personal growth. It can also be a helpful way of working with those who aren't able to put their experience into words. It is not about creating a beautiful art piece but about the process of expression, therefore you don't need to have any previous experience with art materials. People increase their self-esteem and develop a sense of self-efficacy; at the same time, they recognize and manage the possible emotional reactions related to the diagnosis and face a new and complex reality. They are encouraged to construct a new lifestyle and to make a decision regarding personal choices and projects. Counselling has been evaluated by patients very positively (95%), preferring it to psychotherapy sessions (90%)



**Conclusions:** Counselling is a real innovative service for Marfan patients. It identified internal resources improved the quality of life of these people, supporting its strengths and self-determination skills. Patient doesn't change his way of being, but his way of coping with the problem/situation, they collected new information and discovered new points of view.

*"It's not the health worker that offers solutions but the patient who understands his situation will find in himself the correct way for a solution."*

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## References:

- 1: Dietz H. Marfan Syndrome. 2001 Apr 18 [updated 2017 Oct 12]. In: Adam MP, Ardinger HH, Pagon RA, Wallace SE, Bean LJJ, Stephens K, Amemiya A, editors. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle;1993-2018.
- 2: Rogers C. Client-Centered Therapy: Its Current Practice, Implications and Theory. London: Constable. 1951.
- 3: Dunne, M. American Art Therapy Association strategic planning recommendations. Mundelein, IL: AATA.2003.