

Ageing amongst individuals with invisible disorders

The importance of patient organizations

Introduction

Marfan syndrome is a disorder of connective tissue, the tissue that strengthens the body's structures. Disorders of connective tissue may affect the skeletal system, cardiovascular system, eyes, and skin.

Advances in medical treatment have greatly improved the outlook for persons with Marfan syndrome, but ageing and increasing health problems create challenging situations in daily life. Especially challenging is the risk of aortic rupture, which necessitates immediate surgical intervention.

Persons with Marfan syndrome in Norway can contact one of the 16 national resource centres for rare disorders for highly specialized information and support ('Norwegian Model'). They may also contact the patient organization for Marfan syndrome. The aim of this study is to establish knowledge about ageing and needs for services amongst individuals with Marfan syndrome.

Methods

Qualitative focus group interview with eight persons having Marfan syndrome and qualitative in-depth interviews with ten persons having Marfan syndrome (>40 years of age). The interviews are transcribed and analyzed in a life course theoretical perspective.

Results

Findings show that the balancing act of wanting to function 'normally' and at the same time accepting the diagnosis and its life course consequences may be difficult. Many feel that they 'age' prematurely.

The Marfan Association helps individuals managing challenges in daily life and their health situation. Meeting other people with the same diagnosis may be of importance as to:

- accept the diagnosis and reflect on the importance of life course adaptation
- gain understanding of the physical condition, psychological challenges, and ageing processes
- realize that for some reducing or terminating employment activities may be an option, may be the best solution
- change in self-understanding
- learn how to economize energy to enjoy prioritized activities
- find a group to identify and share experiences with
- put pressures on authorities to expand knowledge and services

Conclusion

The mix of public services, resource centres, and the Marfan Association are all necessary parts of the Norwegian model supplying services throughout the life course for people with Marfan syndrome. There is still a lack of knowledge of the life long implications of living with this syndrome, and a great need for information within the health and social services.

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'I think the Association has rescued many by accepting living with Marfan although it is pretty hard.'

