

Experiences of ageing in persons (40+) with a rare disorder

Aim

The aim of this study is to provide knowledge about experiences of ageing amongst individuals with a rare disorder. A rare disorder in Norway, is defined as a diagnosis affecting less than 100 : 1 000 000. Advances in medical treatment have greatly improved life course prospects for persons with rare diagnoses. A few decades ago many died young, today they may now reach an advanced age. There are very few studies concerning life course and ageing experiences in this group.

What does visibility/invisibility of disability, social stigma, and having a rare disorder mean for life course experiences?

Methods

- Qualitative focus group interviews with 6–10 individuals (37 persons >40 years) within the following diagnoses:
 - Congenital limb deficiency (complete or partial absence of one or more limbs)
 - Hemophilia (bleeding disorder in which the blood doesn't clot normally)
 - Marfan syndrome (genetic disorder of the connective tissue)
 - Short stature due to skeletal dysplasia
 - Turners syndrome (genetic disorder that affects a girl's development)
- Qualitative in-depth interviews with 45 persons (>40 years) with these disorders.

The interviews are transcribed and analyzed in a life course theoretical perspective. The analyses are ongoing. Ageing experiences are analyzed comparing life experiences among the five diagnosis groups.

Results

Lack of knowledge regarding rare diagnoses within the ordinary health and welfare services often aggravates health problems and reduces quality of life. Individuals in the five diagnosis groups have access to national resource centres for rare disorders which provide for information and support. Sixteen such centres constitute the 'Norwegian model' of services to people with rare disorders.

- The diagnostic process for some disorders is at times random. For some, a diagnosis is made in adulthood.
- 'Ageing' may be experienced earlier in life than expected.
- Fatigue and pain are common experiences.
- Individuals attempt to live a normal life course, this sometimes requires significant effort.
- Visible and invisible impairments, stigma, ageing, and increasing health problems create special challenges in daily life, differing between the groups and amongst individuals.
- Trying to conceal their disability and escape stigma takes efforts.
- Many become overachievers trying to balance their activities compensating for impairments.
- Employment is important for identity and normal life, and leaving work at an early age may be distressing. Improvement in workplace modification strategies may allow for extended participation in employment for this group.
- The local health and social services lack knowledge, continuity, and personnel.

Conclusion

People with rare diagnoses have special challenges connected to ageing in many aspects of daily living. There is still a lack of knowledge of the life long implications of living with a rare disorder and there is a great need for information within the health and social services.

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'They didn't live so long before, but now they get their heart changed and everything – so now we're also getting old!'

