«I want to share my experience with others»
A case study with an elderly woman

Unni Steen, MSc, Senior Occupational therapist
Gunnar Riemer, MD, Neurologist

TRS National Resource centre for rare Disorders
A part of Norwegian National Advisory Unit on Rare Disorders (NKSD)

Doing a case study with an elderly woman with amyoplasia
- A joint process

- The main parts of the study
- Key milestones in the joint process
- Some considerations
Background and purpose

• Amyoplasia – the most common form of Arthrogryposis multiplex congenita (AMC)
  • Characterized by:
    – typical deformities of the joints
    – atrophied or absent skeletal muscles of the limbs
    – all four extremities are usually affected
    – large variation regarding affection and function
    – sporadic / not genetic
  • Knowledge concerning adaptation to adult life and aging is limited
  • The woman at the age of 93 wanted to share her experiences, this justified a single case study

Aims

• To gain knowledge about various aspects of living a long life with amyoplasia:
  - changes of the physical limitations
  - participation
  - coping strategies in daily activities
  • Knowledge of importance for people with the disorder, their families and professionals in order to:
    - support function-enhancement
    - understand changes in ability
    - learning that living a long and active life with amyoplasia is possible
Methods

• Framework: The International Classification of Functioning, Disability and Health (ICF)

• A joint process, where the woman’s contribution were essential in forming the study
• Clarifications about her being recognizable

• The medical history covered the last three decades
• Physical examinations from the last ten years
• The psychosocial history, activities and participation from several conversations
• Autobiographical essays
• Personal photographs

Results

- body functions and structures

• Affected in all four extremities

• Twenty one surgical procedures during childhood and adulthood, mostly in lower extremities

• Walking without aids up to the age of 37

• Muscular force declined gradually, firstly in the legs and later in the arms
• Used electric wheelchair from about the age of 60
• Good general health up to the age of 86
• Musculo-skeletal pain decreased during ageing
**Education and employment**

- High school degree at the age of 21
- Started to study chemistry, but had to stop because of the Second World War
- Education in stenography and type writing
- Full-time employed in 32 years as a health secretary and as a social care worker

**Recreation and leisure**

- Learned to play piano and violin
- Enjoyed travelling by her own car
- Engaged in the “Norwegian association for AMC” and in the founding of TRS Resource centre
Daily living

- An active life, especially up to the age of 50
- As independent as possible, by using assistive devices – some designed by herself
- The life became more challenging as she got older

Personal reflections on her life

- Despite of physical limitations she participated actively in both general life demands and in social relationships - up to the age of 85
- Felt obligated to renounce marriage and having children
- She lived a long life, and experienced changings in the conditions for living with a disorder. In the last decades she felt that society became more open-minded towards people with disabilities
Some considerations
- limitations and challenges

- Limitations with case studies

- We had for a long time wanted to write about the experiences of this woman

- Objections and challenges

- The way we addressed them

- Some themes she did not wanted us to write about

Writing the article

- Conversations in her home about her life with amyoplasia

- Read the draft article together and collaborated on the design of it

- Picked out pictures

- She expressed that she felt she was taken seriously and was pleased to get this opportunity to share her experiences in an article

- She approved the final result, but unfortunately died before the article was published
Conclusions

• Case studies of elderly persons are important for increasing knowledge about how disorders develops and for better understanding of transition processes

• Reading about an active life with a disorder and coping strategies in a lifespan might encourage people with the same disorder, their families and the professionals

• The joint process made the persons voice heard and strengthened the credibility

• In a case study it is important to consider ethical issues, regarding anonymity and ability to consent

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Case study

Amyoplasia: a case report of an old woman

• Gunnar Riemer & Unni Steen
• 1 Asklepios Fachklinikum Lübben, Kinder und Jugendpsychiatrie, Lübben, Germany
• 2 TRS – A National Centre for Rare Disorders, Sunnaas Rehabilitation Hospital, Nesoddtangen, Norway