



# Experiences with pregnancy and pregnancy-related physiotherapy in women with Charcot-Marie-Tooth disease. A qualitative interview study.

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# Disclosure

- I have no actual or potential conflict of interest in relation to this presentation.





# Background

- **Charcot-Marie Tooth (CMT)**
  - ***Often manifests before reproductive age***
  - ***Heterogenous with varying symptoms and progression***
  - ***Often lack of knowledge among healthcare professionals<sup>1</sup>***
- **CMT and pregnancy**
  - ***1/3 of women have reported worsening of, or new, CMT-related symptoms during pregnancy or after childbirth<sup>2,3</sup>***
  - ***↑ muscle weakness and sensory impairment, ↑ incidence of cramps, pain and fatigue<sup>1</sup>***
  - ***Muscle weakness may persist after childbirth<sup>2</sup>***
  - ***.....but: Increased fatigue and joint pain are common among all pregnant women, making it difficult to know whether they are normal pregnancy symptoms or a result of the disease<sup>4</sup>***



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1. Arnold, McEntagart & Younger 2005
2. Pisciotta et al 2020
3. Rudnik-Schöneborn tta et al., et al. 2020
4. RehabiliteringsCenter for Muskelsvind n.d.



# Background

- **Physiotherapy (PT) and CMT**
  - ***Physiotherapy is recommended for individuals with CMT during pregnancy and after childbirth<sup>1,2,3,4</sup>***
  - ***Although there are few studies on the effect of physiotherapy for individuals with CMT, the results indicate that it is a valuable treatment approach<sup>1,3,4</sup>***
  - ***There is limited research available regarding the experience of pregnancy, early motherhood, and physiotherapy for women with CMT***



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1. Corrado, Ciardi & Bargigli 2016
2. Helsedirektoratet 2019
3. Mathis et al. 2015
4. McCorquodale, Pucillo & Johnson 2016



# Aim

***"What are the experiences of women with Charcot-Marie-Tooth disease during pregnancy and early postpartum, and what experience do they have with physiotherapy?"***



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# Method

- **Qualitative interview study**
- **Digital semi-structured interviews (Microsoft Teams)**
  - *Transcribed using Nvivo software*
- **Phenomenological and hermeneutic theoretical framework**
- **Theme-based qualitative analysis**
  - **Malterud's systematic text condensation<sup>1</sup>**



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1. Malterud 2018

# Material

- **Inclusion criteria:**
  - **CMT-diagnosis**
  - **Childbirth within last 5 years**
  - **Experience with PT related to their CMT**
- **Info about project on the National neuromuscular centre Norway's SoMe-platforms. Interested individuals assessed for eligibility by project leader (AL), then detailed information letters and consent forms were sent**
- **n=4**
  - **CMT type 1A: 3**
  - **Clinical CMT diagnosis:1**
- **All participants were ambulatory, but with varying degree of function**



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# Results

Theme 1: «Bodily changes»

Theme 2: «A new everyday life»

Theme 3: «Physiotherapy and physical activity»



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## Theme 1: «Bodily changes»

- In general positive views on the pregnancy, despite challenges. Some find it difficult to know what issues are related to a “normal” pregnancy vs. pregnancy with CMT
- Increased walking and balance difficulties due to:
  - Weight gain and altered centre of mass/pressure → reduced possibility to compensate with core muscles and vision
  - Reduced sensory function and strength in distal leg muscles
  - ↑ neuropathic pain, especially at night, leads to worsening of daytime fatigue
- Some experienced long-term loss of walking and balance capabilities after pregnancy and the postpartum-period



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## Theme 2: «A new everyday life”

- ↓ sensibility, balance and walking capabilities reduces autonomy when taking care of the child
  - Eg. Difficult to carry a wet baby, change diapers, determine the child’s skin temperature, managing a stroller downhill
  - Baby carriers are helpful, but reduce ability to compensate with vision
- ↑ dependence on partners or other assistants
- ↓ autonomy can lead to frustration and reduced self-worth due to societal views on motherhood
  - Some «hide» their need for help, may impact services provided from the healthcare-system





## Theme 3: «Physiotherapy and physical activity»

- Limited knowledge of CMT among PTs affects compliance and sense of need for follow-up
  - Difference in advice from HCPs related to physical activity may  $\uparrow$  fear for doing something wrong and thus  $\downarrow$  daily activity
- Specific interventions tailored to the individual promotes compliance and a wish to continue treatment
- Need for a holistic view from PTs during pregnancy and postpartum
  - Often too focused on length, strength and mobility without addressing impact of the pregnancy on their CMT and daily life
- Regular physical activity was crucial for maintaining fitness during and after pregnancy, and daily walks with the child  $\uparrow$  coping



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# What do the women need?

- Knowledgeable PTs to
  - Assess gait and balance difficulties, mental health, pain and fatigue during pregnancy and the postpartum period
  - Help with specific core activation interventions
  - A holistic assesment of the resources and challenges for the woman and her family to adapt activites (eg. carrying or bathing the child), assess the need for assistive devices or assistants in daily life
  - Navigate the healthcare system
  - Help shape their perception of the self and their societal role through education on aspects related to CMT and pregnancy



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# Conclusions

- ***Pregnancy and the postpartum period is in essence positive for women with CMT-disease***
- ***Difficult to attribute symptom changes to pregnancy or CMT, but the changes nevertheless pose problems and may decrease autonomy***
- ***There is a need for dissemination of knowledge about CMT-related challenges with pregnancy to physiotherapists and other health care professionals***
- ***Such knowledge is important to address needs and develop robust health care services and empower these women***
- ***Further studies with larger sample sizes are warranted***



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