



LeveNÅ


Enhet for samhandling, livskvalitet og lindring

Adaption and support needs of siblings of children with Metachromatic leucodystrophy

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Metachromatic leucodystrophy (MLD) is a rare progressive disease and represents a major family trauma

HCP is obliged by Norwegian law to provide sibling support

Family centered care highlighted in Norwegian PPC standards



sibling support
within the frames of family life?

How to provide

Method



Interview guide developed in cooperation with parents

Qualitative interviews with six parents of children living with or recently deceased from MLD

Conventional content analysis



Our study



RQ 1: What kind of emotional reactions and behavioral adaptations do parents observe in daily life among siblings of children with MLD?

RQ 2: What do parents perceive as good ways of supporting siblings of children with MLD in daily life?





**Emotional reactions and
behavioral adaptations**

Emotional reactions

«They feel unsafe and are hesitant to spend time with her»

“It has been difficult to talk about him at school... they often start to cry»

“She has this hope that everything is going to be ok someday saying ‘dad are you absolutely sure that Peter is going to die’”

Love and care
Anger and frustration
Fear
Sadness
Long for normality
Hope

Behavioral adaptation

“I cannot get too emotional, if I do, she takes on this comforting role and she is not supposed to have that role”

“He has become quite patient. He must wait a lot, wait, and accept a lot”

«He is extremely social and not a bit shy and I think it's because there is a lot of people in our house all the time”

Maturity

Caring

Appreciate divergence

Patience

Sociability



Sibling support



Resources at home

Assistants

“The assistants will just as well put them on the lap or help them”

Medical and practical aids

“We were offered a hospital bed... but we did not want it, so we made a big round one... The siblings love to play there, and it became an environment that really included them”



Maintaining and building relations

Sibling relation

“I use to let him into the room with Jonas and the assistant in the morning. In this way they have some quality time alone, him and Jonas”

Time with parents

“I find it really important to be aware of him... that he once in a while really needs mum and dad as well”



Support initiatives

Friends and family

“... their aunt and uncle take them out on trips and in the weekend , do what we (parents) are not able to do.”

Systematic care from the welfare system

“Someone that could have met him, played with him, looked at pictures of his brother, and tried to tell him all the stuff that I may not have the knowledge to tell him in the right way”

Information

Total openness

“We chose to tell her that it ends with death, mostly to give her the possibility to join us in the sorrow “

Gradual based on progression

Based on child initiative

«We had a deal that if they asked if he was going to die, we would be honest, but they did not ask until right before he passed away”

To limit anxiety



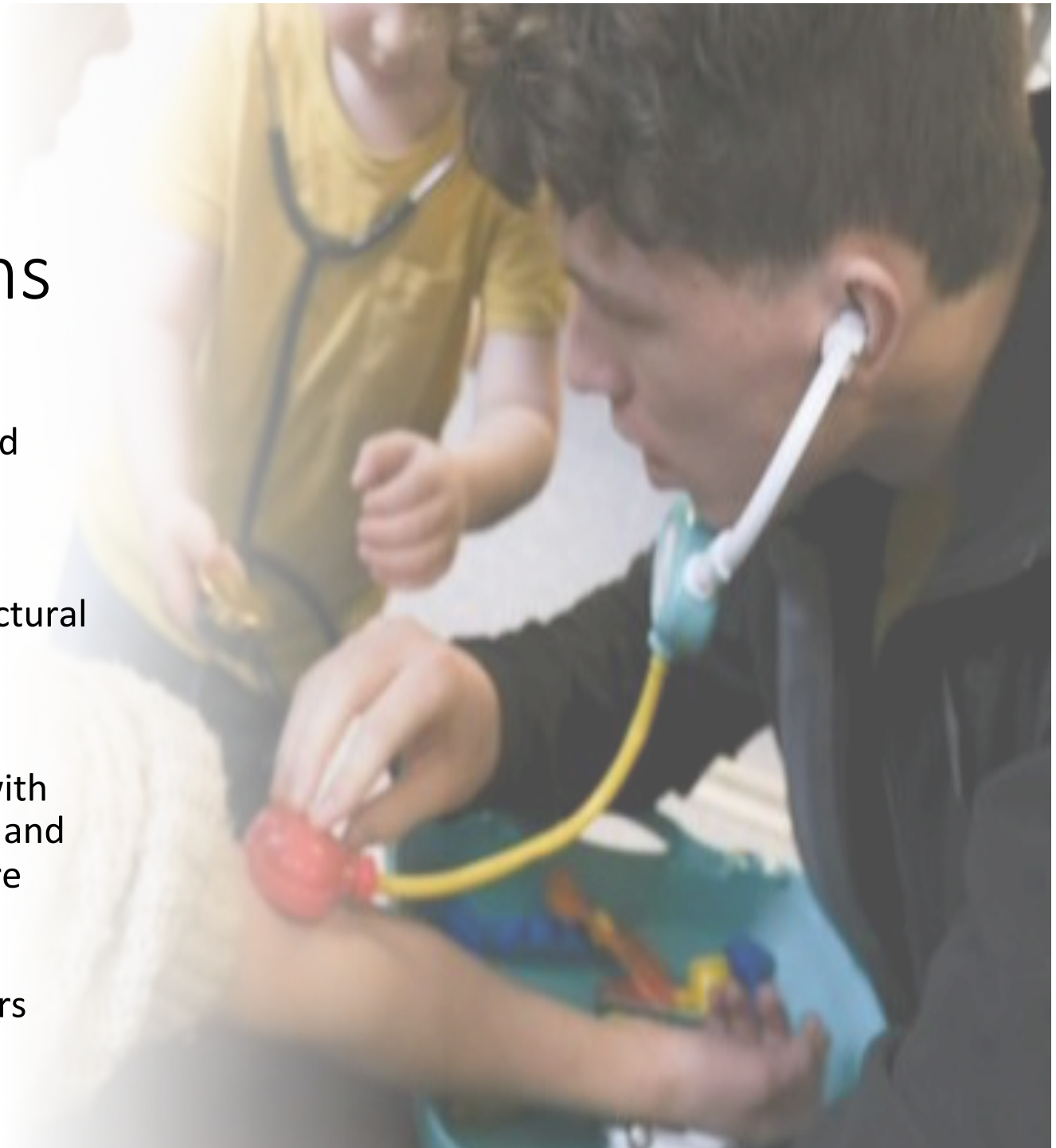
Clinical implications

Mapping reactions and needs in daily life

(Development of structural play observation)

Counseling sessions with kindergartens, school and community health care

Webinars and seminars



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Participants

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