

What do Parents of Girls and Women with Rett Syndrome Worry About?

Jane Lunding Larsen
The Danish Center for Rett Syndrome



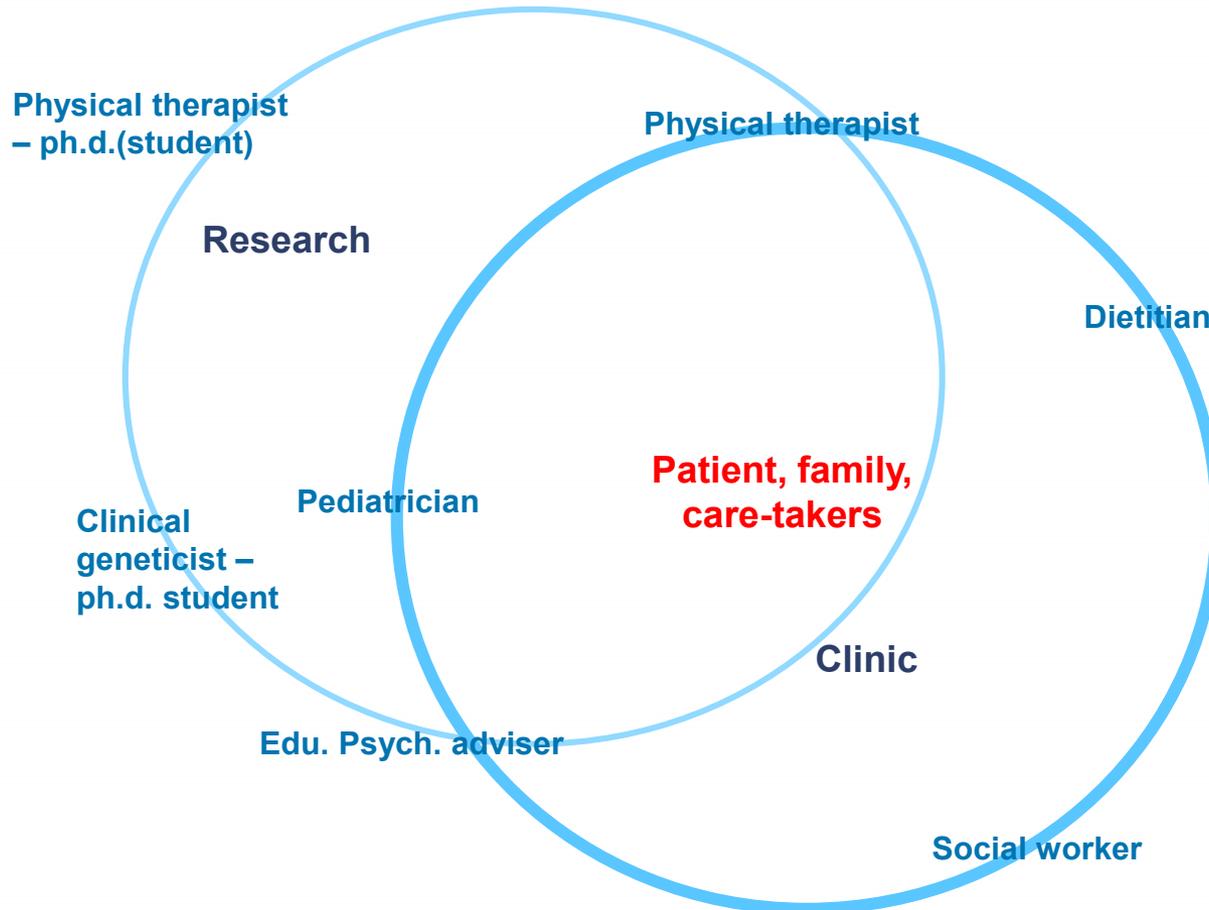
The Danish center for Rett syndrome

Overall aim is to enhance the quality of life for girls and women with Rett syndrome AND their families

The parents (and the rest of the family) have to be "functioning" in order to be able to take care of the girl/woman with Rett syndrome



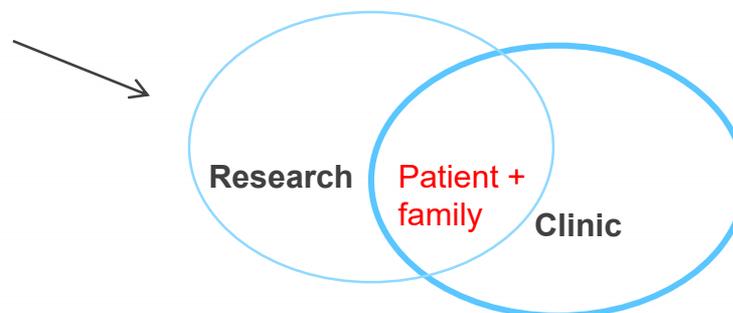
The Danish center for Rett syndrome



”The parents worries project”

Why

Wanted to qualify our clinical focus and counselling, and our research



What

Wanted to find out, what kind of worries the parents had about their girl with Rett syndrome

How

A semistructured questionnaire

The questionnaire

<p>Worry 1:</p> <div style="border: 1px solid black; height: 100px; width: 100%;"></div> <p>During the last month, how much has this been worrying you on a 1 to 10 scale, where 1 is the least and 10 is the most?;</p> <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>8</td><td>9</td><td>10</td></tr></table> <hr/>	1	2	3	4	5	6	7	8	9	10	<p>Worry 3:</p> <div style="border: 1px solid black; height: 100px; width: 100%;"></div> <p>During the last month, how much has this been worrying you on a 1 to 10 scale, where 1 is the least and 10 is the most?;</p> <p> </p> <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>8</td><td>9</td><td>10</td></tr></table> <hr/>	1	2	3	4	5	6	7	8	9	10
1	2	3	4	5	6	7	8	9	10												
1	2	3	4	5	6	7	8	9	10												
<p>Worry 2:</p> <div style="border: 1px solid black; height: 100px; width: 100%;"></div> <p>During the last month, how much has this been worrying you on a 1 to 10 scale, where 1 is the least and 10 is the most?;</p> <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>8</td><td>9</td><td>10</td></tr></table>	1	2	3	4	5	6	7	8	9	10											
1	2	3	4	5	6	7	8	9	10												

The questionnaire

We also asked about

The age of the daughter with Rett Syndrom



Because we wanted to see wether there was a connection between the age of the daughter and the type of worrying

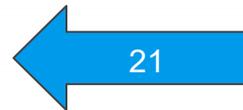
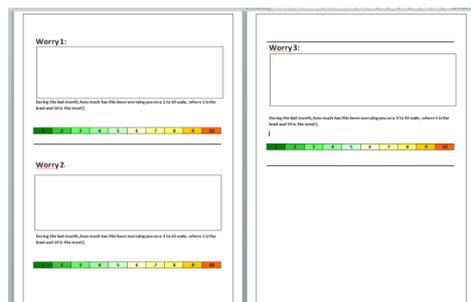
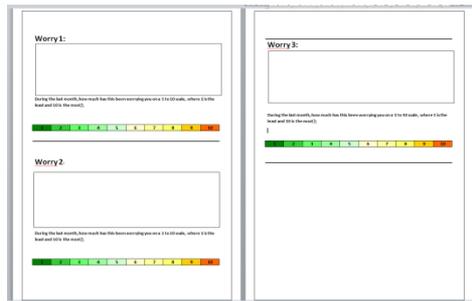


The sex of the parent

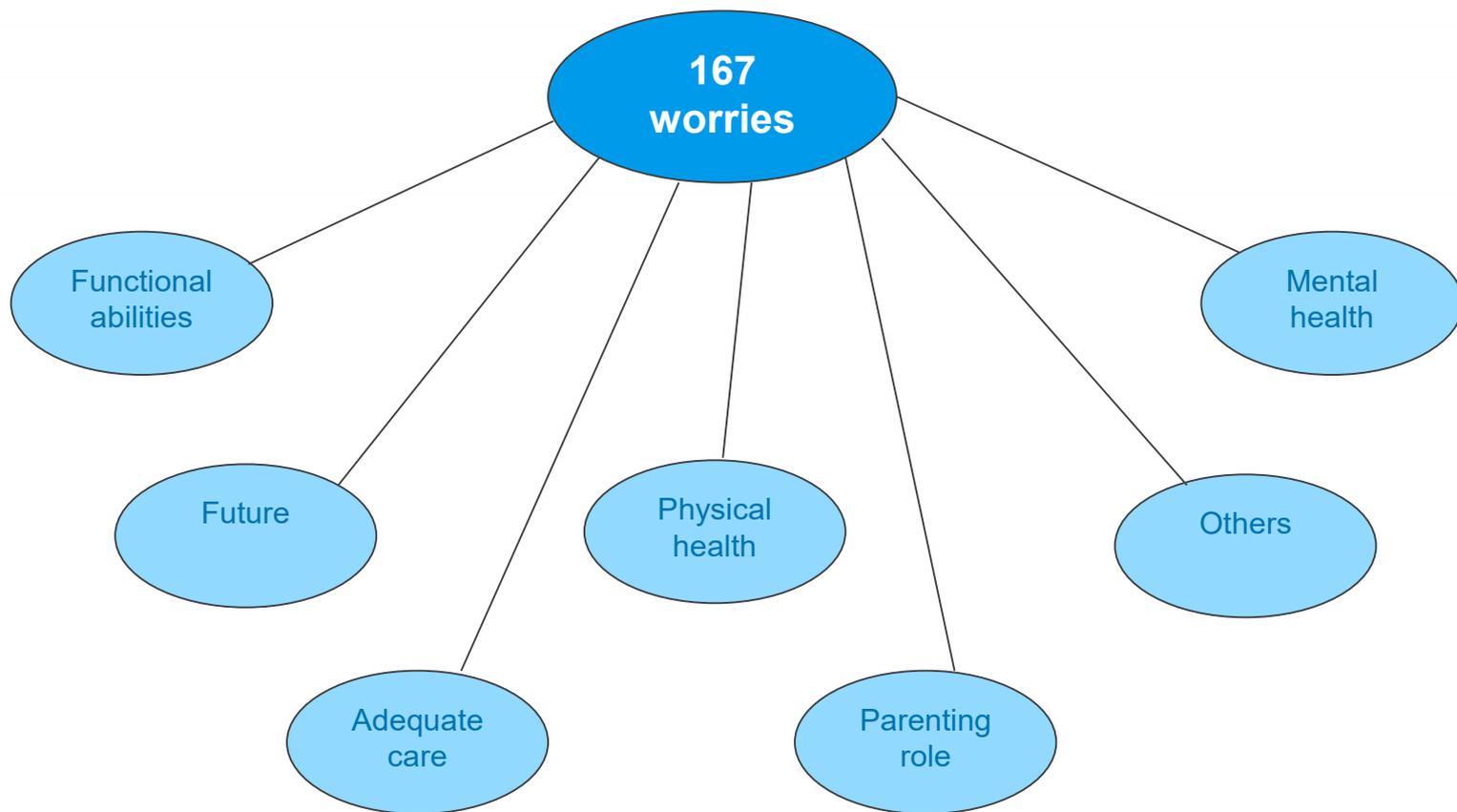


Because we wanted to see, if there was any difference between what the mothers and farthers worried about

The questionnaire



The daughters aged 3-50 years



Functional abilities

Loss of ambulation

Physical activity level

Loss of skills

Ability of learning new skills

Communication (limited skills)

"Her and our ability to communicate. Do we grasp her wants and needs and react appropriately? How do we meet her frustrations when we can't interpret her immediate needs?"

"I think it's difficult to learn my daughter new skills. The very few things I have taught her, I have trained with her for a long time"

"...also that she doesn't get to gait train enough, [she] is still able to walk with support, but without that she can not come home for visits"

Physical healthGastrointestinal
disorder (incl. pain)Acute lung function
(incl. Death)

Scoliosis

Comorbidities

Death/life expectancy

Pain (incl.
undiscovered)

Epilepsy

Weight/nutrition

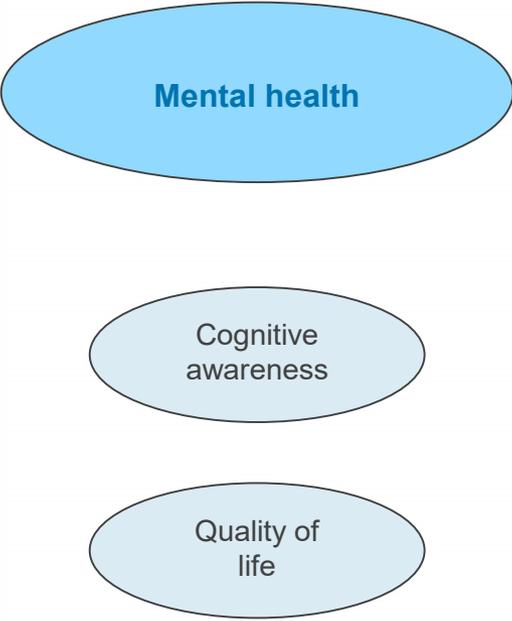
Bonefracture

Heartfunction

"The health is what worries me the most. So far Emmas health is good but what about the future? Will she die early/suddenly"

"That she will get pain, acute or chronic illness without we or others are able to help her"

"The epilepsy. My daughter has had two seizures last summer, but we haven't discovered any more seizures at the moment. I sincerely hope that she/we will avoid the epilepsy"

**Mental health**

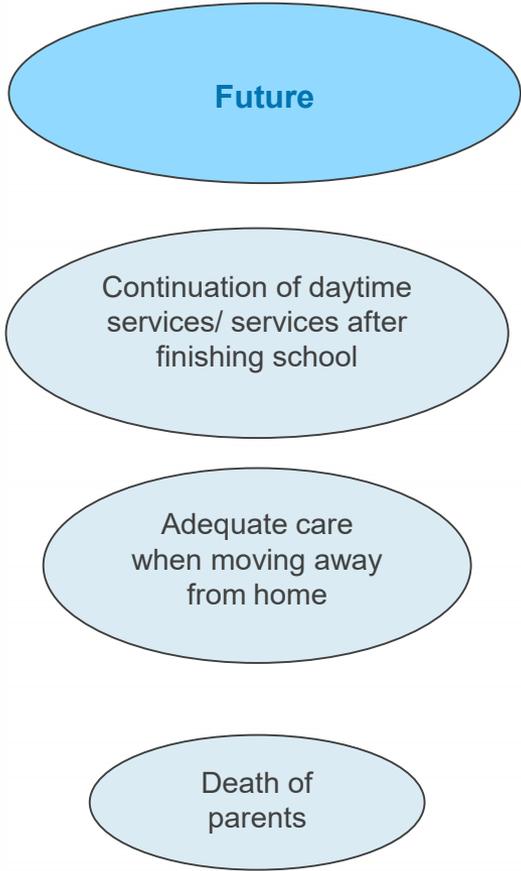
Cognitive awareness

Quality of life

”How she experiences everything. I wonder, if she have any thoughts about how often we see each other, and how she experience to live in her own flat [in a nursery home] and her every day life.”

”The mental [health]. Does she understand more than we know? Do we accidentally talk over her head? Do we “forget” her in the daily life, and does she just become this “thing” that comes along with us?”

”Her mental condition. How much does she actually know [about her condition] her self? And why is she sometimes sad ([I] know that she isn’t in pain) – it’s more a unhappy sadness?”



Future

"Who will take responsibility/decisions when we (her parents) are no longer here?!"

Continuation of daytime services/ services after finishing school

"[...]I worry the day will come where we have to accept that we can't do this [take care of the daughter at home] anymore and have to move her to a institution. That would ruin me completely."

Adequate care when moving away from home

"What will happen the day that I/we are not here anymore? Will her interests be taken care of in a way that is good enough? And will she understand why she doesn't see us anymore?"

Death of parents

Adequate care

Residential facilities

When not with parents

Respite

Activities & participation

- Stimulation/activities
- Limited participation

”Does she receive the necessary care at her residential home? I think so, yes, but cutbacks and downsizing staff indicates that something, which should have been quality time, instead becomes a question about ”storage”.”

”Will the new institution be good enough to hear her seizures?”

”[I worry] wether she’s doing alright; Doesn’t sit and stare into the wall [or] watching tv the whole weekend. Does she get her CPAP three times a day. Is she offered to go to the toilet every 3-4 hours.”

Parenting role

"It's a problem for us to stimulate her enough/as much as we would like to. All the practical stuff takes a lot of time and energy, both for her and for us. She can't really do any stimulating activities on her own."

Doing enough
for her?

"Have I been able to do [the parenting role] well so far; can she sense that I'm sick to my stomach in frustration and that I absolutely don't want to be a handicap-mom anymore?"

Aging parents

"We have a good visuel [eye]contact with our daughter and know her well. But we are guessing when it comes to her health problems. So far we have nailed it. But I worry about the day when we stand completely blank and don't have any clue about how we can help her"

Other

"[I worry] that my daughter get's excessive medicated"

Too much medication

"Her siblings – they need a break from there sister, [I] think a lot about how they are doing and how much this affects there everyday life."

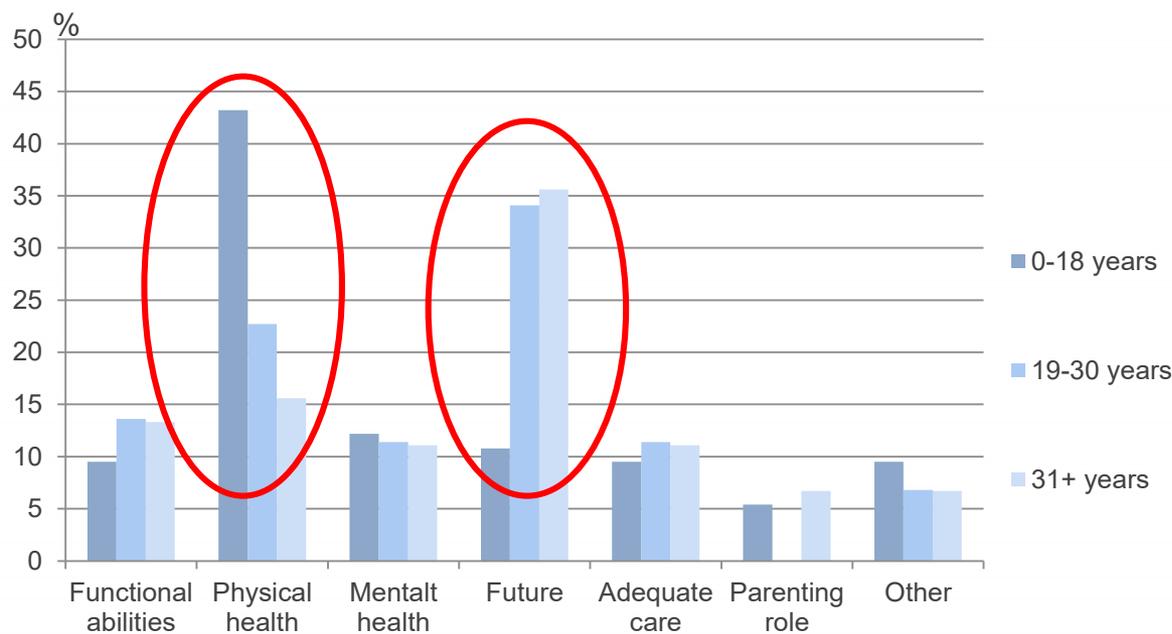
Family life/siblings

"Do the municipalities have to economize so much that the future simply will be a unpleasant storage of my daughter"

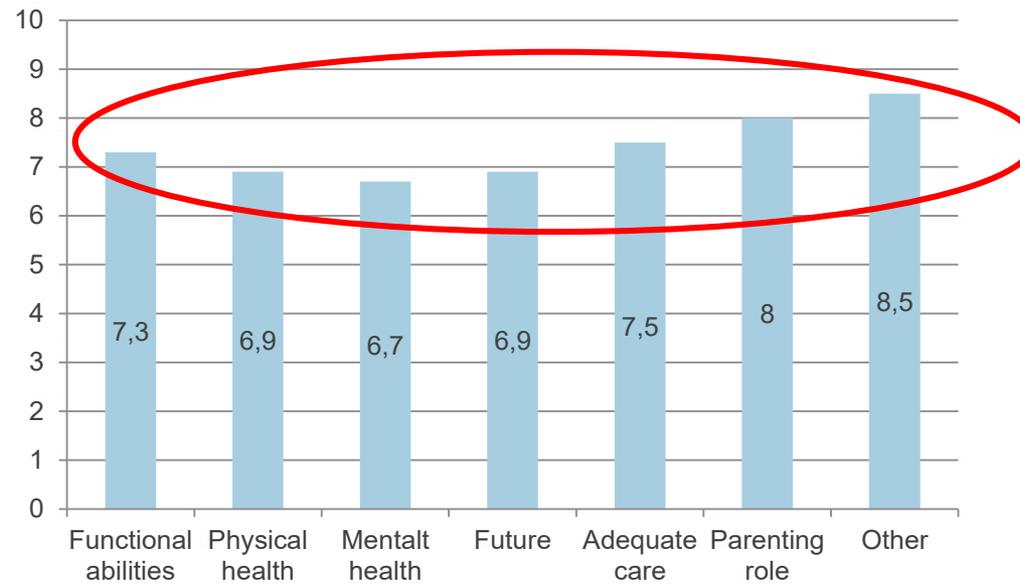
Cooperation with social services

Economic ressources in municipalities

Type of worry in relation to age of the daughter



Type of worry in relation to average level of worry - on a 1-10 scale



Conclusion

- Parents to girls and women with Rett syndrome have a wide range of worries about their daughter with Rett syndrome
- The cohort was too small to tell, whether there was any differences between the type of worrying the mothers and the fathers had
- A difference was seen in the type of worries parents of girls aged 0-18 years had, compared to the type of worries parents to women aged 19 and older had
 - Age 0-18, often worried about physical health
 - Age 19+, often worried about the future
- The level of worry was high



**Thank you for
your time**