How can parental perspectives inform research into the communication abilities of those with intellectual disability? An example from Rett syndrome.

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Presentation overview

- Background:
  - Communication & communication partners
  - Rett syndrome
- Study:
  - Research questions
  - Methods
  - Results
- Parental perspectives informing practice & research
- Conclusion
Communication partners

• Parents with a child with severe intellectual disability are often skilled communication partners

• Skilled communication partners can inform:
  – Assessment
  – Intervention
  – Evaluation
Rett syndrome diagnostic criteria

Main Criteria
• A period of regression:
  • Loss of purposeful hand skills
  • Loss of spoken language
• Gait abnormalities
• Stereotypic hand movements

Supportive Criteria
• Diminished response to pain
• Intense eye communication
• Breathing disturbances & bruxism
• Laughing/screaming spells
• Sleep problems

• Abnormal muscle tone
• Scoliosis/kyphosis
• Growth restriction
• Small cold hands & feet
Research questions

1. How do girls and women with Rett syndrome engage in communicative interactions in everyday contexts?

2. What factors act as barriers or facilitators to successful communicative interaction?
Methods

• 16 interviews with purposively sampled Australian parents
• Interview guide
  – ICF (World Health Organization, 2001)
  – Receptive & expressive communication, social interactions, factors influencing communication
• Analysis:
  – Directed content analysis (Hsieh & Shannon, 2005)
  – ICF (World Health Organization, 2001)
<table>
<thead>
<tr>
<th>Girl/woman with Rett syndrome</th>
<th>Age (years)</th>
<th>Age when speech regressed (months)</th>
<th>Able to say single words</th>
<th>Level of assistance required to walk</th>
<th>WeeFIM score</th>
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Multimodal communication

- The type & number of modalities used changed according to the context
- One modality could have a variety of functions

[ With like her food… she will look and lean towards whichever she wants ] – Sarah’s mother
Expressive communication

“Deciphering whether she’s trying to tell us something else or she’s in pain, that’s really hard to decipher.” - Julia’s mother
Expressing discomfort & protesting

[“Use your eye to make the choice, tell us what you’d like” and she’ll look at the object, look back at us, look at the object.] - Janet’s mother
Making choices

“Dad”
Pulling people’s hair

Raspberries
“Mum”

Screaming
Requesting attention

[cheeky grin]
[big massive eat to eat grin]
[giggles]
[laughter]
[vocalisations – “jibber jabber” “calm sounds”]

Expressing happiness
Receptive communication

• Understanding language

“not because of a lack of understanding it’s more because of Rett syndrome, the ability to voluntarily do something”

• Understanding symbols

“at school last year they had to get up and pick their name off the board and she’d always find it with her eye and then she’d get her head and touch it”
Body functions and structures

[ Some days obviously things will come out really easy and fluently and then other days there’s… even up to a couple of minutes delay for her to be able to respond ]
- Tara’s mother Psychomotor control

“If the environment’s too busy… it’s too much for her, that’s when we sort of lose her, it’s like she’s got so much stimulation going in it’s just… too much for her” – Joanna’s mother Sensory functions

“I think if she’s weary or tired she doesn’t respond at all.”
- Julia’s mother Consciousness
Environmental factors

[ If it’s food normally we’d get the response straight away… with other things it might take a bit longer ]
- Ashley’s mother Food

“It’s about… being patient as well because she does get frustrated if people… ask her to do something and then wait two seconds”
- Joanna’s mother Waiting

[ She responds really well to people who get down at her level… the music teacher is really good with Sarah… she stops and looks in Sarah’s eyes and gets in her face and Sarah responds really well to that ]
- Sarah’s mother Establishing eye contact
Activities

“She can’t just go and walk to get what she wants. I think that makes it harder.”
- Rebecca’s mother Mobility

She’s had the same teacher for 3 years and I think that’s made a really big different... by having the same program and by having things constantly reinforced... it’s definitely meant she’s been able to move forward and improve her communication skills
- Isobelle’s mother Learning

[ She can’t even point. She can’t isolate her index finger… it’s completely incumbent on the person that she’s communicating with to be looking at her ]
- Janet’s mother Hand function & establishing eye contact
Communicative interactions

**Siblings**
'We'll often have a situation where... our 10 year old will say "no mum she wants this" and it's exactly what Janet wants and I can't even give you... a logical explanation for that except that I think they are sisters and at some level [her sister] has a strong sense of what Janet needs' (Janet's mother).

**Parents**
'I'll sing ring-a-ring-a-rosy and... when it gets to the part fall down I stop and lean in and wait for her and she anticipates it, she has to fall down, so she'll start to lean backwards... I'll say the words fall down and she sits on her bottom. And then you do cows are in the meadow buttercups it's time to jump and I pause and I wait and she'll start to pull herself up on my hands' (Sarah's mother).

**Peers**
'Last year... Janet made a little friend in the kindergarten class... this little girl... just gets Janet and... she uses a combination of being quite physically close to Janet, asking Janet questions, looking at her face and that's kind of their communication... and for whatever reason it works very well for those two. It's beautiful actually... I think it's the first time that we could say that Janet has a friendship that's completely independent of anyone other than who she just is' (Janet's mother).

**Professionals**
'The carers can say to Natalie... "how are you this morning Nat?" and she'll say "good" and... they'll say "we're going swimming" and she'll say "yes"... they can get answers from her' (Natalie's mother).

**Extended family**
'An aunty rings us up and says "put her on" so I put her on and she's speaking to her on the other end and she's saying her things like her Monicas and her happy birthdays and whatever. So she's responding in her language and they do it like that' (Monica's mother).
Parental perspectives informing assessment

Rett syndrome

- Levels of alertness
- Apraxia
- Sensory integration

Mobility
- Hand abilities
- Learning abilities

Participation

- Interaction with communication partners
- Motivating items/activities
- Physical & sensory environment

Age

(World Health Organization, 2001)
Parental perspectives informing intervention

Rett syndrome

Gross motor skills
Functional hand skills
Promote learning

Sensory integration

Use motivating items/activities
Communication partner training

Consider age appropriate interventions

Participation

(World Health Organization, 2001)
Parental perspectives informing research:

• As it is happening...
  – Reference groups

• In the future...
  – Qualitative studies to build understanding that can be empirically investigated
  – Eye gaze research example in Rett syndrome
Conclusion

• Girls & women with Rett syndrome can engage in meaningful interactions
• Assessment & intervention needs to consider the parental perspective
• The parental perspective can inform research
Parents with a daughter with Rett syndrome who participated in this study
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