



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

The Family Impact of Caring for a Child with Severe Neurological Impairment

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Definition of SNI



Severe Neurological Impairment results from disorders of the central nervous system which arise in childhood, leading to motor impairment, cognitive impairment and medical complexity, where much assistance is required with activities of daily living. The impairment is permanent but can be progressive or static.

Allen J, Brenner M, Hauer J, Molloy E, McDonald D. Severe Neurological Impairment: A delphi consensus-based definition. European journal of paediatric neurology : EJPN : official journal of the European Paediatric Neurology Society. 2020;29:81-6.

Family Wellbeing of Children with SNI

Background



- **Caring for children with chronic neurological disorders affects the family ⁽¹⁾**
- **Much of existing research on parents**
- **Importance of the sibling relationship ⁽²⁾**
 - Relatively little research
- **Variation in effects reported**
 - Methods used
 - International experience varies
 - Variety of diagnoses



1. Knecht C, Hellmers C, Metzger S. The Perspective of Siblings of Children With Chronic Illness: A Literature Review. *Journal of pediatric nursing*. 2015;30(1):102-16.
2. Kramer L. Learning emotional understanding and emotion regulation through sibling interaction. *Early Education and Development*. 2014;25(2):160-84.

Family Wellbeing of Children with SNI

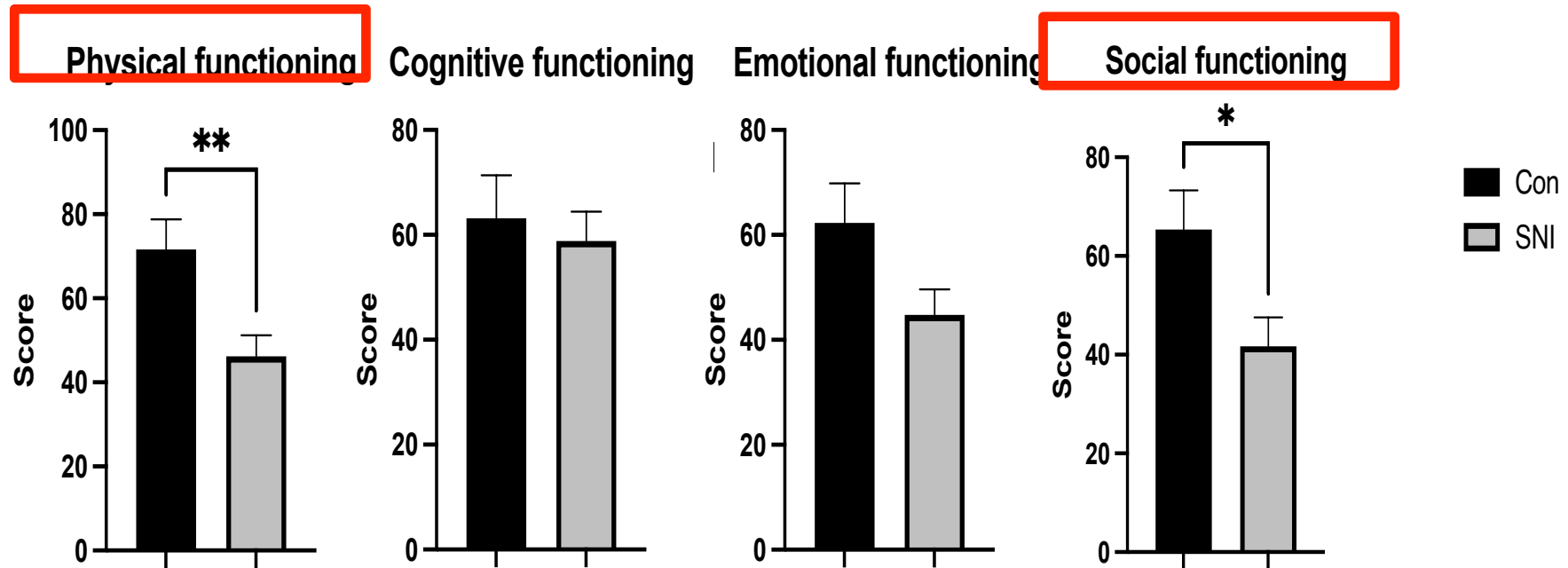
Methods



- **PedsQL™ FIM, PedsQL™**
- **Focus group**
 - Lead facilitator – consultant psychiatrist with experience in such groups
 - Semi-structured interview protocol
 - Open ended questions followed by more specific probing questions
 - Audio recorded and later transcribed verbatim
 - Interpretive Phenomenological Analysis
 - Repeated reading of the transcript with emergence of themes

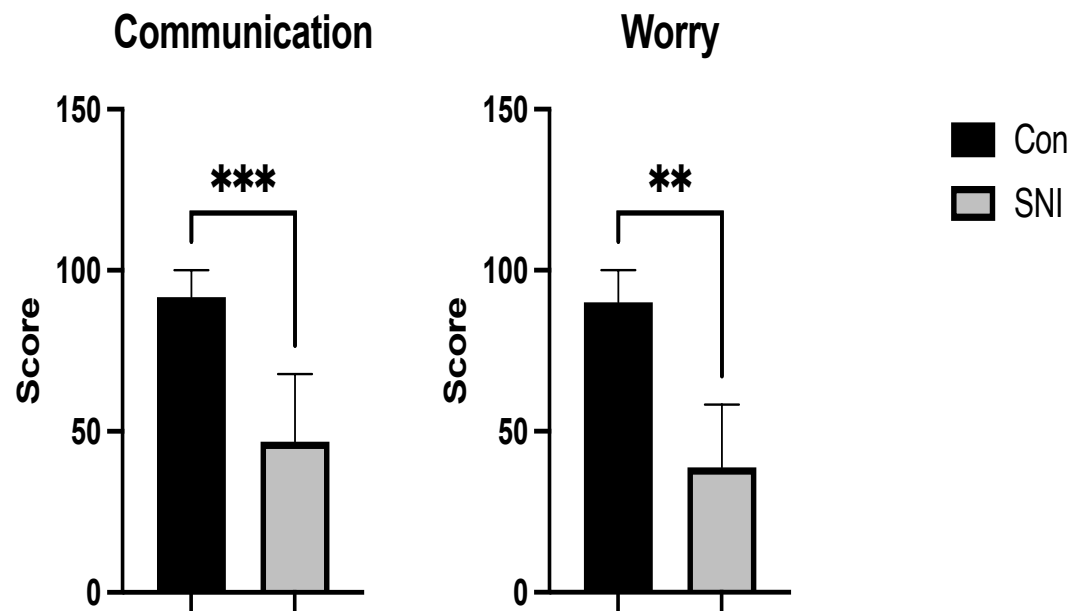
Family Impact

Parental physical and social functioning is lower in those who care for child with SNI



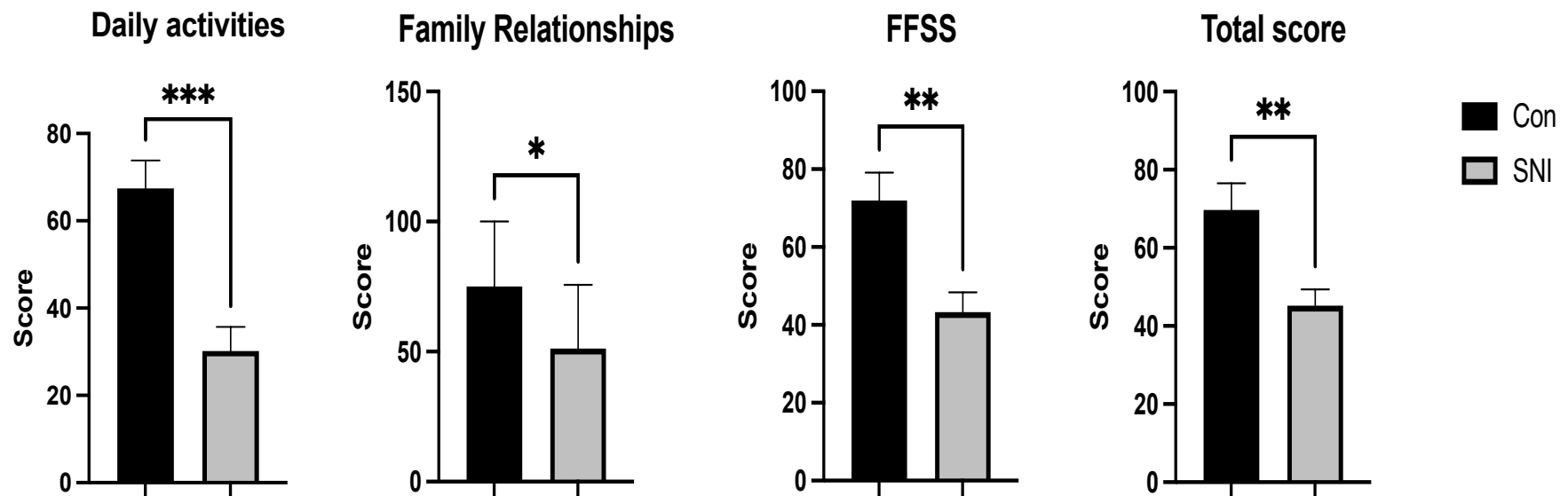
Family Impact

Parents of children with SNI more likely to have communication issues and to worry



Family Impact

Family functioning significantly impacted



Sibling focus groups

Demographics



- **11/28 families initially invited to participate**
- **7 siblings initially recruited for the focus group**
- **4 presented for participation**
- **The siblings were relatively homogenous**
 - aged between 12 and 14
 - 2 male, 2 female
 - Irish nationality
 - Recruited from families attending a single paediatric complex needs clinic
 - No sibling pairs

Sibling focus groups

Theme 1: Making sense of their situation



- **Diagnosis and related concerns**
 - Only 1 knew sibling's diagnosis
 - All spoke openly about differences
 - "Scary" situations
- **Normalising**
 - Disruption to routine
 - Overall acceptance
- **Conflicts from outside world**
 - Internalisation of understanding, attaching meaning and managing communication



Sibling focus groups

Making sense – selected quotes



- *“She’s in a wheelchair, she can’t walk, she can’t talk, **she can’t do anything on her own**, she’s deaf in one ear and she has epilepsy”*
- *“...it (seizure) was **a very scary experience**”*
- *“I feel like I’m **getting used to it** now”*
- *“I don’t really get to go out much... because **I need to come back in to help** my mum again”*
- *“And also I’d wait to be friends with someone to let them know that (siblings) have disabilities, not like **embarrassed** of it or anything... **most people don’t know how to respond to it**”*



Sibling focus groups

Theme 2: The sibling relationship in the family



- **Family relationships**
 - A knowledge of parents extra caring responsibilities and the stress this causes
 - Effect on one-on-one time with parents
- **Role, responsibility and function**
 - Varying levels of care expected of them
 - None expressed resentment or anger
 - Positive changes including increased maturity and empathy



Sibling focus groups

The sibling relationship – selected quotes



- *“Just like pick it [stress] up like, I know my mam.”*
- *“**My mum does everything**...So she’s constantly on the move”*
- *“No, they have time, **we do get to talk but not all the time.** Sometimes we do”*
- *“If my mum isn’t able to if she misses a feed, I know exactly what she would do so **I’ll get that done.**”*
- *“In my family not even my nanny or granddad knows him like I do, **I know him inside out.**”*
- *“it helped me **mature a lot** more than I*



Sibling focus groups

Theme 3: Personal impact



- **School and holidays**
 - Attendance
 - Difficulty going on holidays
- **Changes to daily routine**
 - Mixed experiences
 - Daily routines revolving around sibling with
 - Enjoying time alone, solo activities
- **Living with COVID-19 restrictions**



Sibling focus groups

Theme 4: Encounters with healthcare professionals



- **Some negative experiences, being talked down to, frustration**
 - *“I feel like why would you put him on, leave him on it medicines **as a test subject... only one of them works** which is his seizure one”*
 - *“It was **frustrating ... they just wouldn't listen** because my mum is not a doctor so apparently she doesn't know what she is talking about.”*
- **Some positive experiences**
 - *“I'd say the **support they get is pretty good**”*
- **Looking to the future – suggestions to help**
 - Online support groups



Discussion & future directions

- **A major effect on parental QoL, family functioning and overall family impact**
 - Filled by mothers almost exclusively
- **Sibling PedsQL™ scores not significantly different**
 - Parental shielding?
 - Not independently filled
 - Tool too simple to capture complexities
- **Focus group**
 - Demonstrated the complexity of the situation, resilience, areas where we need to improve
- **Future directions**

Acknowledgements



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Thank you!

