What do children say about daytime and nighttime incontinence?
A qualitative exploration of 30 children with urinary incontinence

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Urinary Incontinence

Up to 10% of children
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Viewed through the lens of the parent or provider
Urinary Incontinence

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Knowledge gap on children’s perspectives
Methods

Interview guide
  Child psychologist
  Survey methodologist
Semi-structured interviews
  Pediatric urologist
  Researchers
Methods

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  Child psychologist
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Urinary incontinence
Functional etiology
Ages 8 - 17
English fluency
Can interview
Methods

Interview guide
- Child psychologist
- Survey methodologist
- Semi-structured interviews
  - Pediatric urologist
  - Researchers

Qualitative analysis
- Content expert
- Qualitative researchers

Urinary incontinence
Functional etiology
Ages 8 - 17
English fluency
Can interview
Participant Cohort

n = 30

Median Age 11.5

53% Female

3% Stress Incontinence

20% Daytime Incontinence

47% Daytime and Nighttime Incontinence

20% Monosymptomatic Enuresis (MNE)

10% Non-MNE
Themes

Life Impact
Themes

Life Impact

Mental Health
Themes

- Life Impact
- Mental Health
- Adaptations
Themes

- Life Impact
- Mental Health
- Adaptations
- Practical Implications
Impact on Life

Catastrophizing: 17%
Accepting: 40%
Minimizing*: 43%

Incontinence “is the worst thing that happened to me”

Accidents are “a part of life sometimes”

*Statements may reflect minimizing or coping behavior

Excerpts from patient interviews

Accidents play “no big deal” in my life
Mental Health – Self Esteem
Results: Mental Health – Negative Emotions

- Embarrassment: 77%
- Anxiety: 67%
- Sadness: 47%
I feel embarrassed. I feel disappointment in myself. I feel like I’ve failed.
Anxiety

Yeah, it makes me anxious. . . sometimes it does make me want to not do things
Sometimes it’ll make me depressed, because it’s like *this happens so many times*, and it will not go away, and it kind of brings me bad memories again.
Responses and Adaptions

**Behavioral Modifications**
- Increase voiding frequency
- Regulating fluid intake
- Staying awake longer
- Playing near bathrooms
- Avoiding laughter

**Material and Physical Adaptations**
- Incontinence underwear
- Incontinence safe bedding
- Change of clothes
- Changing sheets
- Hiding clothes/sheets
Practical Implications

- Sleepovers: No Effect (23%), Negative Effect (20%)
- Sports: No Effect (20%), Negative Effect (27%)
- Schoolwork: No Effect (53%), Negative Effect (53%)
First in-depth qualitative analysis to show...

- Significant impact for sleepovers
- High self-esteem
- Embarrassment and anxiety are prevalent
- Many behavioral and physical adaptations
Thank you
Mental Health – Negative Emotions

23 subjects
Embarrassment

20 subjects
Anxiety

14 subjects
Sadness
Practical Implications

- Sleepovers: No Effect, Negative Effect
- Schoolwork: No Effect, Negative Effect
- Sports: No Effect, Negative Effect

7 Sleepovers, 16 Schoolwork, 16 Sports
Practical Implications

Sleepovers
Schoolwork
Sports

No Effect
Negative Effect
Practical Implications

No Effect

- Sleepovers: 7
- Sports: 6
- Schoolwork: 16

Negative Effect

- Sleepovers: 16
- Sports: 6
- Schoolwork: 8
Practical Implications

<table>
<thead>
<tr>
<th>Activity</th>
<th>No Effect</th>
<th>Negative Effect</th>
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<td>Sleepovers</td>
<td>7</td>
<td>16</td>
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Knowledge gap on children’s perspectives
Strengths of Study

• First, in-depth qualitative analysis

• Perspective of children
Framework analysis

Research Categories

• Contextual
  – Identify the form and nature of what exists
    • Attitudes and Perceptions
    • Nature of experiences
    • Needs
• Diagnostic
• Evaluative
• Strategic

Steps

• Familiarization
• Identifying a thematic framework
• Indexing
• Charting
• Mapping and interpretation