A Phenomenological Exploration: Caring for People with Down Syndrome

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Problem

- There is a growing need to understand the stresses, imbalances, joys, and supports experienced by caregivers of individuals with Down syndrome (DS).
Significance:

Down syndrome facts:

- Down syndrome is the most common genetic intellectual disability in the US
- 1 in every 691 babies are born with DS
- 400,000 people in the United States
- ~800,000 people providing care to people with DS

(National Down Syndrome Society, 2012)
Purpose

To explore the lived experience of caregivers of people with Down syndrome.

- Leisure
- Stressors
- Coping
- Supports
The literature revealed:

- A need for more specific information (Daunhauer & Fidler, 2011)
- Negative effects to physical, social, psychological, and financial stability (Dizzao-Miller, Samuel, Marnas, & Welker, 2014)
- Negative effect to role (Thinnes and Padilla, 2011)
- Higher levels of stress, adjustment difficulties, poorer coping (Povee, Roberts, Bourke, & Leonard, 2012)
Methodology: Design and Participants

Design: Transcendental Phenomenology developed by Clark Moustakas
- Phenomenology is finding the essence of a phenomenon
- Semi-structured interview

Participants criteria:
- Formal or informal caregivers 18 years of age or older
- English speaking
Recruitment Method

- Convenience sampling
- Down Syndrome Association of Los Angeles
- Club 21
- 6 participants
<table>
<thead>
<tr>
<th>Participant Name</th>
<th>Gender</th>
<th>Age Range</th>
<th>Individual with Down syndrome name</th>
<th>Individual with Down syndrome age</th>
<th>Formal or Informal caregiver</th>
<th>How long have they been caregiving</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karen</td>
<td>F</td>
<td>50s</td>
<td>Sam</td>
<td>23</td>
<td>Informal (parent)</td>
<td>23 years</td>
<td>Public Information Specialist, Regional Center</td>
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<tr>
<td>Jenna</td>
<td>F</td>
<td>50s</td>
<td>Rebecca</td>
<td>14</td>
<td>Informal (parent)</td>
<td>14 years</td>
<td>MSOT student</td>
</tr>
<tr>
<td>Denise</td>
<td>F</td>
<td>30s</td>
<td>Emily</td>
<td>32</td>
<td>Informal (sister)</td>
<td>7mos</td>
<td>Library staff, prospective OT student</td>
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<tr>
<td>Pamela</td>
<td>F</td>
<td>50s</td>
<td>Diane</td>
<td>17</td>
<td>Informal (grandchild)</td>
<td>16 years</td>
<td>Special Education Paraprofessional</td>
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<tr>
<td>Trisha</td>
<td>F</td>
<td>50s</td>
<td>Zed</td>
<td>15</td>
<td>Informal (parent)</td>
<td>15 years</td>
<td>Housewife</td>
</tr>
<tr>
<td>Violet</td>
<td>F</td>
<td>50s</td>
<td>Vanessa</td>
<td>16</td>
<td>Informal (parent)</td>
<td>16 years</td>
<td>Housewife</td>
</tr>
</tbody>
</table>
Data Analysis and Results

5 Emerging Themes

- Constant Care
- Social Supports
- Advocating
- Caregiver Stress
- Positive Outlook
“I’m not supposed to be anywhere without her and they never see one without the other. That’s how it is. I tell you we are just so close. We have to do things together. I plan my weekends around her. We have our own little ritual that we do together.” (Pamela)
“I’ve really seen the need for connection, and that is probably the number one stress reducer … the one thing that has helped me probably, personally, is being in a support group with other moms and getting all of their feedback.”

(Jenna)
Advocating for individuals with Down syndrome

“I felt like [the social worker] wasn't really listening to Emily or what she wanted to do. And that was really stressful because it made me see how someone with a cognitive disability, how very little agency they have sometimes even within the systems that are supposed to support them and help them to be more independent.” (Denise)
Caregiver stress

Lack of Leisure Time

“Non existent”
“Barely making it”

Safety Concerns

Trisha’s son, Zed, was a “runner”

Worries for the future

“Sometimes you’ll have dark moments when you think “what’s it going to be like down the road? Who’s going to watch her?” (Jenna)
Caregiver stress

Health of the individual with DS

“The medical stuff seemed so stressful in the early years.” (Jenna)

Chronological Age vs. Developmental age

“I’m kind of expecting him to be the man of the house and a responsible young person yet at the same time I’m making requests of him that are childlike.” (Karen)
“It can be really rewarding...he’s really loving. He comes up to me every morning while I’m making lunches for everybody and he gives me a big hug, you know, there are a lot of good parts to it. We’ve met a lot of incredible people.” (Trisha)
While caregiving is a positive experience, it also includes a lack of leisure time and an increased need for self care, areas which can be addressed through occupational therapy.
Application to Occupational therapy

- Informational support to caregivers about Down syndrome
- Advocate for the caregiver, to the caregiver
- Program development
Limitations

- Secondary diagnoses
- All were informal caregivers
Ethics

- Approval from IRB review board
- NIH Certification
- Password protected files
- Pseudonyms
- Destruction of material
Questions?
References


References