DAUGHTERS OF MOTHERS WITH MULTIPLE SCLEROSIS: THEIR EXPERIENCES OF PLAY

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Influences
• Play Around the World (see presentation Tuesday, 2:00–3:00pm, Room B)
• MS ActiveNOW
Play

Definition:
• Play is individually defined, depending on one’s own play experiences and personal perspectives (Tekin & Tekin, 2007).

Importance:
• Crucial for the health and well-being of children (Pellegrini & Smith, 1998a).
• Contributes to children’s psychological well-being (Partitt & Eston, 2005), cognitive performance, friendships, social organization, and social skills (Pellegrini & Smith, 1998a).

Phenomenon of Interest
• The nature and extent of caregiving may be inappropriate for their age and developmental level (Aichdige & Becker, 1999; Ireland & Pakenham, 2010; Warren, 2007).
• Concern that when children become caregivers, they are assuming adult nurturing roles during times when they themselves should be nurtured (De Judicibus & McCabe, 2004).
• Parental disability may also decrease opportunities for families to play together (Warren, 2007).
Purpose of Study

Numerous researchers have examined the experiences of young caregivers (e.g., Aldridge & Becker, 1999; Warren, 2007), but few have specifically examined the intersection of their experiences as caregivers and play.

Given the importance of play, the purpose of this study was to describe how daughters who are caregivers to their mothers with multiple sclerosis experience play.

Methodology

• This study was phenomenologically informed, which describes the meaning of people’s lived experiences (Creswell, 2007).

• Researchers attempt to describe shared occurrences and “grasp the very nature of the thing” (van Manen, 1997, p. 163) across its many variations (Miles & Huberman, 1994).

• Phenomenology can provide important insights into the profound disruptions that occur with MS (Toombs, 1995).
Participants

- 4 Canadian Caucasian women were interviewed, aged 19-26.
  - Mothers tend to prefer daughters’ support over their sons (Suitor & Pillemer, 2006).
  - This is an appropriate age range for young caregiver participants, as it reflects the increased age of children living at home with their parents (Packenham & Bursnall, 2006).
- All were caregivers for their mother with MS and from lone-parent families at one time.
  - In Dearden & Becker’s (2004) report on young carers in the UK, they found that the majority of people with care needs were mothers.

Data Collection Methods

- Demographic Information (e.g., type of mom’s MS, physical activity interests, co-residency status, age when mother diagnosed)
- Audio-taped Interviews
  - One-on-one (semi-structured)
    - Tell me about a time (story/ies) when helping your mom was memorable for you.
    - Focus group (unstructured)
- Artefacts
  - Representations of their experiences of play
    - E.g., Mom’s baseball glove, jazz photo…
- Member checking (unstructured)
- Field Notes
Data Analysis

- Data was analysed thematically, line-by-line (van Manen, 1997).
- Family systems theory (Turnbull & Turnbull, 1997) provided the conceptual framework for analysis and interpretation of the data.
  - “For those interested in the family, a systems approach is an essential conceptual tool” (Beavin Bavelas & Segal, 1982, p. 107).

Results

Three themes and supporting subthemes emerged:

- Being a good daughter
  - Assuming extra duties
  - Guilt and worry
  - Growing up quickly
  - Delaying leaving home
- Blurred relationship boundaries
  - Restoring the daughter relationship
  - Needing adults to step in
- Encumbered play
  - Solitary play
  - Lost play opportunities
Being a Good Daughter

- Carrying out their duties was viewed as part of being a “good daughter” (Haley).

- The daughters spoke of assuming extra duties beyond that of their role of “good daughter” and this impacted their relationship with friends.

- Felt guilty and worried if they left their moms.
  - Holly: Feelings of guilt “made it hard to enjoy things” because even when I was out playing with friends, I’d “be worried or feel bad that I wasn’t home taking care of [my mom]”.

Blurred Relationship Boundaries

Restoring the daughter relationship

- The participants spoke of at length of desiring more than a care recipient-caregiver relationship with their moms.
  - Spend more time together as mother and daughter.

Needing Adults to Step In

- Holly would “escape” to play or simply relax whenever her mom had a visitor because “it was the one chance I had to not worry ‘cause somebody was there”.
Encumbered Play

- Play was described as making the best of a difficult situation, an “escape” from the role of caregiver, lacking in spontaneity, and framed by the support of others.
- Organized activities that Holly participated in were those that her “friends did” and “it wasn’t ever...what I was interested in”.
- No play role model
- Solitary play
- Lost Play Opportunities

Discussion

- They wanted to be “good daughters”, but they also felt remorse for missed play and socialization opportunities.
- Once the families evolved beyond the daughter as caregiver, the daughters renewed an authentic relationship with their mothers.
Discussion

• The daughters’ experiences support an association between parental role models and children’s activity levels (e.g., Anderssen & Wold, 1992; Freedson & Evenson, 1991).

• Impoverished play experiences in childhood carried over into their adult lives as described in their limited play and physical activity pursuits as adults.

Limitations and Future Directions

• Would have been valuable to get other family members’ perspectives.
  • To ensure a whole-family approach is taken, getting the perspectives of parents and any other members of the family unit would be beneficial.

• The label of “young caregiver” has been criticised as being an adult-imposed term on a childhood experience.
  • Rather than using a “young caregiver” approach, Banks et al. (2001) propose that ethnographies of children of parents with disability are likely to be more helpful in developing theories based on the ways in which children view the world.

• Not “true” lone-parent families.
Final Thought...

Elizabeth: I find that [people] won’t ask how I’m doing and that’s just kind of tough. I know my mom is having a hard time too, but it’s really affecting me as well, and so I think people kind of just neglect that and forget about it”.

Thank You!