The Experience of Mothers with Multiple Sclerosis

Catherine Willson (willson-c@sky.com) • Marina Usai and Giovanna Konrad; Italian Multiple Sclerosis Society

BACKGROUND
- Medical literature focusing on negative outcomes
- Influence of Disabled peoples' and Feminist movements
- Role of professionals
- Lack of skills of professionals and lack of resources
- Barriers – physical, environmental and attitudinal

RESEARCH AIMS
- How have mothers maintained their role since the onset of their MS; have they needed support and if so, how do they view that support?
- How do external barriers, such as environmental, societal or attitudinal, impact on the women's experience of being a disabled mother?
- Is the time of diagnosis relevant in the impact of MS on the women's experience of motherhood?
- Do wider influences in Italian society, such as the church and government policy, impact on the experiences of disabled women in Italian society?

INCLUSION CRITERIA
DIAGNOSIS OF MS:
At least one child under the age of 18 still living at home. Five women from each of the following groups were recruited:

GROUP 1
Those who have some level of impairment which impacts on their everyday function. Level 4.5, 5 or 5.5 on the Expanded Disability Status Scale (EDSS)

GROUP 2
Those with a greater degree of physical impairment, which regularly impacts on their everyday function. Level 6 or 6.5 on the EDSS

GROUP 3
Those who are severely physically impaired and are regular wheelchair users. Level 7, 7.5 or 8 on the EDSS

STUDY DESIGN
- Qualitative study explored lived experience
- 15 women participated in face to face in-depth interviews
- 7 of these women were interviewed for a second time, follow up on specific issues
- The interviews were recorded, transcribed into Italian and translated into English
- Following analysis, summaries were sent to participants for their comments
- Emerging themes were identified

EMERGING THEMES

A. SOURCES OF SUPPORT:
- PRIVATE HELP:
  - Self-funded
  - Empowering
  - Can be avoided as being indicative of dependency
- FAMILY:
  - Help spontaneously given
  - Can be overwhelming
  - Lack of understanding
- FRIENDS:
  - Act as distraction
  - Offer help like all mothers do between each other
- STATE:
  - No expectations
  - Do not deliver
  - When is provided, not certain or empowering
- FROM WITHIN:
  - Fighting a battle
  - Value of motherhood role
  - Determination
  - Strength
  - Positivity
  - Openness in communication
  - Disclosure of impairment
- MEDICAL SUPPORT:
  - Amount of information given
  - Influence in decision making around pregnancy
  - Confidence gained from medics

B. CHILDREN:
- GIVE STRENGTH
- ADAPT THEIR EXPECTATIONS
- ASSOCIATED STIGMA
- AMBASSADORS FOR FUTURE GENERATIONS
- SUFFERING
- INDEPENDENCE:
  - Self respect
  - In case MS worsens
  - Normal family expectations
- UNDERSTANDING AND ASSISTANCE
- TEENAGE PROBLEMS-EXACERBATED
  - Withdrawal
  - Disciplining differently

C. WIDER SOCIETY:
- IGNORANCE:
  - About MS
  - About disability in general
  - From the women themselves prior to having MS
  - Resentment regarding facilities and adaptations for disabled people
- PITY:
  - Gives further strength
  - Leads to annoyance
- ADMIRATION:
  - Leads to feelings of empowerment
- PHYSICAL BARRIERS:
  - Challenges
  - Insurmountable so avoid
  - Access to transport
  - Acceptance of how it is
- DISABLED ADAPTATIONS
  - Facilities do not work or are not available
  - Lack of funding and provision of equipment
  - Value of ASM

KEY POINTS
- There was a poor awareness of multiple sclerosis and of the requirements and adaptations required by disabled people generally within wider society.
- The state provides little support in terms of financial help, support workers or equipment.
- Women were largely supported by family members or privately employed help.
- Physical barriers, particularly access to buildings and public transport impacts on the mothers’ ability to fully participate in their children’s lives.

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