

Relationships, caregiving and Multiple Sclerosis: Gender and perceptions of care

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This qualitative research study attempted to understand and unpack the caregiving experience in the illness of Multiple Sclerosis (MS). Ten couples were interviewed separately and later as a dyad to discuss care, care responsibilities and support systems to see how gender influenced either the caregiving or care receiving experience. The purpose of this research was to explore, develop, and understand perceptions of care between care providers and caregivers of MS under the lens of feminist care theory/ethics of care within a social model of disability.

Caregivers and those diagnosed with MS experience the caregiving relationship in a variety of ways where gender does indeed influence the experience of care. Gender provides a dimension for understanding the social construction of the disease including daily responsibilities of both the care giver and care receiver. Participants were acutely aware of gender when required to complete a care event or task outside of traditional gender roles. The social construction of gender provided a point of awareness for participants to examine care roles. Those tasks falling outside traditional gender roles were frequently brought to consciousness and provided an area of potential provocation.

Additionally, this research examined care needs and the role of social support in the care experience. Care needs differed among participants depending on the availability of resources. Resources include: financial, time and social support. Access to these various resources affected the outcome of the care situation. Gender in turn influenced the understanding and use of resources as a dynamic in the experience. The social construction of gender also affected participants' ability to clarify and understand their experience in terms of accessing resources.