

Concepts Important for Multiple Sclerosis Patient Caregivers: Systematic Literature Review of Qualitative Studies

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INTRODUCTION

- Multiple sclerosis (MS) is a chronic, degenerative, demyelinating disease with an unpredictable and heterogeneous disease course.¹
- Common symptoms of MS include fatigue, sexual and bladder dysfunction, pain, cognitive dysfunction, and mood changes.² These symptoms can be disabling to patients with MS and present many challenges for those providing care.³
- Although little is known about the burden on caregivers of patients with MS, data that describe the impact of MS on caregivers' lives are important to improve support and care in the long term.⁴
- A full understanding of the experiences and views of caregivers can be gained from studies using a qualitative approach.⁵

OBJECTIVE

- To identify concepts that are important to caregivers of patients with MS.

METHODS

- A systematic literature search was conducted using MEDLINE and PsycINFO.
- The prespecified search terms for qualitative studies on the experiences of caregivers of MS patients through September 1, 2015, are shown in Table 1.

Table 1. Terms used in the literature search

MEDLINE	PsycINFO
Multiple sclerosis[MeSH] AND (qualitative research[MeSH] OR interview, psychological [MeSH] OR interview[MeSH] OR interviews as topic[MeSH] OR focus group [MeSH] OR personal narratives as topic[MeSH])	Multiple sclerosis[APA Thesaurus] AND (qualitative research[APA Thesaurus] OR interviews[APA Thesaurus] OR grounded theory [APA Thesaurus] OR (grounded OR phenomenological OR focus OR narrative OR verbatim).ti.ab)
Both searches were limited to human studies published in English with available abstracts.	

Selection process

- Once the references had been retrieved, abstracts and titles were reviewed according to the following criteria:
 - Inclusion criteria:
 - Focused on patients with MS;
 - Qualitative study;
 - Describes concepts of importance from the proxies'/caregivers' perspectives.
 - Exclusion criteria:
 - Not specific to MS;
 - Quantitative study;
 - Qualitative data from the clinicians' perspective;
 - Qualitative data describing single-case studies;
 - Dissertation article;
 - Review.
- When insufficient information was provided from the abstract, full-text articles were reviewed.

RESULTS

- Figure 1 shows the numbers of studies that were identified, included in, and excluded from the study.
- Twenty-one published studies met all of the predefined inclusion criteria and were included in the study (Table 2).
 - Ten studies were from Europe, seven were from North America, and four were from Australia and New Zealand.
 - Three studies exclusively described experiences of the children of MS patients, ten were specific to the impact of MS on the lives of the patient's spouse or partner, and the remaining eight described the experience of children, spouse/partner, sibling, next of kin, and/or friends of MS patients.
 - Sample size across all studies ranged from 4 to 530 caregivers.
 - The majority of the included studies (16 of 21) used individual semi-structured interviews to collect data. Three additional studies used a focus group approach, one used unstructured in-depth interviews, and one used narrative interviews.

Figure 1. Flow diagram of study search methods and review process

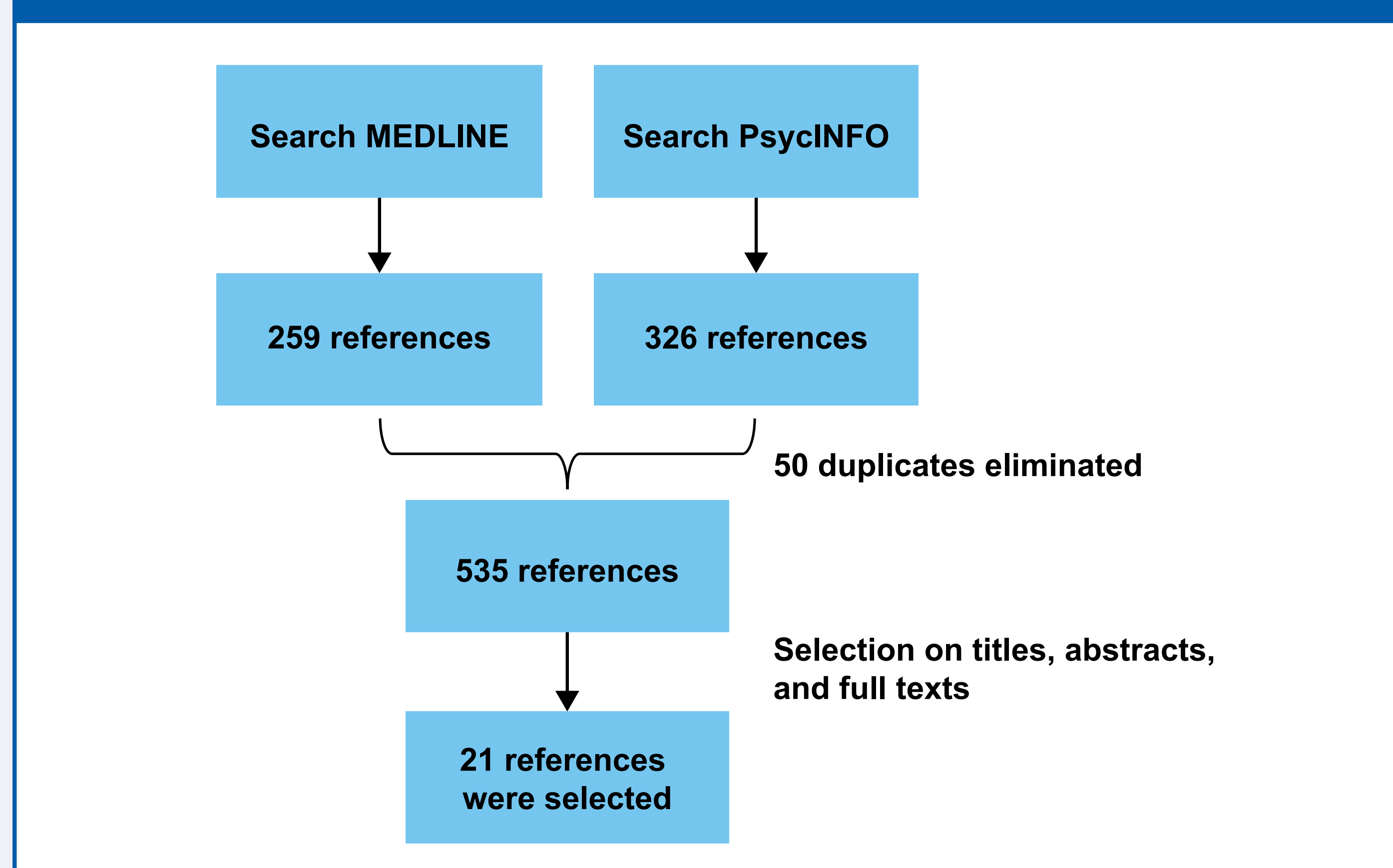


Table 2. Summary of included studies from the literature search

Study	Number of participants	Study design	Concept					
			Emotional impact	Coping and adjustment to MS	Social and informal support	Relationships with patients	Impact on family and everyday life	Financial/career issues
Experience of children of patients with MS								
Jonzon AJ, Goodwin DL (2012) ⁶	4	Focus group interviews	•		•	•	•	•
Bogosian A et al (2011) ⁷	15	Semi-structured interviews	•	•	•	•	•	
Turpin M et al (2008) ⁸	8	Semi-structured interviews	•	•				•
Impact of MS on the life of a patient's spouse or partner								
Chen H, Habermann B (2013) ⁹	20	Semi-structured interviews		•				
Boland P et al (2012) ¹⁰	14	Semi-structured interviews	•	•				
Mutch K (2010) ¹¹	8	Semi-structured interviews	•			•	•	•
Starks H et al (2010) ¹²	16	Semi-structured interviews		•		•		
Bogosian A et al (2009) ¹³	15	Semi-structured interviews	•	•	•	•	•	•
Blank CW, Finlayson M (2007) ¹⁴	4	Semi-structured interviews		•	•			
Cheung J, Hocking P (2004) ¹⁵	10	Unstructured in-depth interviews		•	•	•	•	•
Boeije HR et al (2003) ¹⁶	17	Semi-structured interviews	•	•	•	•	•	•
Koopman W (2003) ¹⁷	15	Focus group interviews			•		•	
Heward K et al (2006) ¹⁸	9	Semi-structured interviews					•	
Experiences of parents, partners, children, relatives, and/or friends who act as caregivers								
Hughes N et al (2013) ¹⁹	40	Narrative interviews			•			
McCurry MK (2013) ²⁰	6	Semi-structured interviews	•		•		•	•
Buchanan RJ, Huang C (2012) ²¹	530	Semi-structured interviews	•					
Bowen C et al (2011) ²²	25	Semi-structured interviews	•		•	•		
Finlayson M et al (2008) ²³	302	Semi-structured interviews	•	•	•			
Liedström E et al (2008) ²⁴	44	Semi-structured interviews	•				•	
Wollin JA et al (2006) ²⁵	24	Semi-structured interviews	•		•		•	•
McKeown LP et al (2004) ²⁶	16	Focus group interviews	•		•	•		•

- Through review of these studies, six concepts that are important to caregivers were identified:
 - Emotional impact;
 - Coping and adjustment to MS;
 - Social and informal support;
 - Relationships with the patient;
 - Impact on family and everyday life;
 - Financial/career issues.

CONCLUSIONS

- Disability or impairment due to MS has a profound impact not only on patients with MS but also on their caregivers' quality of life.^{3,4,27}
- The qualitative studies included in this systematic review have identified the following six concepts that are important to caregivers:
 - Emotional impact;
 - Coping and adjustment to MS;
 - Social and informal support;
 - Relationships with the patient;
 - Impact on family and everyday life;
 - Financial/career issues.
- These concepts will inform further studies of the challenges facing caregivers and may be of use in creating resources to provide support.

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