Ethnicity Affects the Experience of Family Caregivers of People Living with Severe MS: Findings from a Cross Sectional Survey

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Background The influence of ethnicity on family caregivers (FCG) of people severely affected by multiple sclerosis (PwMS) is unknown.

Aim To compare experiences of White British (WB) and Black Caribbean (BC) FCGs of people with severe MS.

Design Cross-sectional survey including ratings of caregiver burden and met/unmet needs. Open questions explored the cultural influence on the main effects of caring, its rewards and difficulties, and changes required to improve caregiving experiences.

Setting/participants FCGs of BC and WB PwMS with Expanded Disability Status Scale ≥6 living in London.

Results 39 FCGs representing 43 BC and 43 WB PwMS were interviewed. More BC caregivers were females caring for parents/offspring who resided elsewhere. Self-reported caregiver burden was similar across groups. Unmet needs common to both groups included timely access to health/social services, requiring more information about MS and its effects, and greater involvement in planning treatment and care. BC FCGs differed from their WB counterparts; they possessed little knowledge of MS, its complications and were more reticent about caring roles which prevented them accessing necessary support. They also reported more financial concerns.

Conclusion FCG’s from both ethnic groups required greater responsiveness and support from formal services. We observed issues specific to FCGs of BC PwMS that caused distress. Health professionals must be mindful that those from ethnic groups may possess little knowledge or experience of living with MS and relevant services. They also need to sensitively advise on managing financial issues.

REFERENCES
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