Assessment and management of sleep disturbance in people with MS: a survey of clinical practice

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On behalf of Therapists in MS (TiMS) Research Group

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Therapists in MS (TiMS)

Therapists in Multiple Sclerosis (TiMS) is an initiative which brings together allied health professionals from across the UK who share a special interest in Multiple Sclerosis – currently about 180 members.

TiMS Research Group Aims

- Select and answer clinical research questions
- Assist novice researchers
- Educate (themselves and others) through process of undertaking research projects
- Create opportunities for multi-centred research
Process

- National call for research questions – 15 responses

- Question selected: “How is sleep disturbance managed by therapists and nurses?”

- Literature review undertaken to determine:
  - Was the answer already available?
  - Was the question answerable?
Background: Sleep Disturbance

- Frequently reported in MS; far more common than in the general population (Brass et al 2010).

- Adversely affects quality of life and is related to increased risk of morbidity (Caminero & Bartholomew 2011).

- Growing evidence to support clinical effectiveness of specific non-pharmacological treatments, either alone or in combination with drugs (Sateia & Nowell, 2004).

- No literature describing what constitutes routine practice by nurses and allied health professionals.
Objective

- To gain an overview of the management of sleep disturbance by UK nurses and allied health professionals involved in the care of people with MS.
Research approach and Methodology

• Cross-sectional survey using convenience sampling

• Sample: Health professionals attending the annual MS Trust Conference, UK
  - All delegates invited to participate
  - No exclusion criteria
The survey instrument

• No relevant survey questionnaire identified in literature → survey questionnaire developed

• Questionnaire development:
  - Views and resources sought (via face to face and TiMS web-based discussion forum)
  - Draft questionnaire developed
  - Questionnaire piloted with 20 therapists / nurses
  - Questionnaire refined, re-piloted with 5 therapists / nurses
Survey instrument

- 16 closed questions with categorical response options
- One open ended question for general comments
- Estimated completion time 15 minutes
Survey instrument

Divided into 4 parts:

1. Demographic data – e.g. gender, profession, work setting (6 items)
2. Whether and how sleep disturbance is assessed (4 items)
3. How sleep disturbance is managed (3 items)
4. Self-rating of knowledge and confidence in managing sleep disturbance (2 items)
Data collection

- All delegates provided with survey questionnaire in delegate packs
- Request to complete questionnaires and hand in to collection boxes during the 3 day conference period
- Participation was voluntary and anonymous
- Consent assumed if questionnaire completed and handed in (outlined in participant information sheet)
Results

- 71% response rate (181 / 256 delegates)
- 93% female (168/181)

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Nurses</td>
<td>58%</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>13%</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>21%</td>
</tr>
<tr>
<td>Others</td>
<td>9%</td>
</tr>
<tr>
<td>e.g. Dr’s, speech &amp; language therapists, psychologists, academics</td>
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<table>
<thead>
<tr>
<th>Work setting</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Part of multidisciplinary team</td>
<td>74%</td>
</tr>
<tr>
<td>MS specific setting</td>
<td>58%</td>
</tr>
<tr>
<td>Neurology specialist setting</td>
<td>29%</td>
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## Results: Demographics (n=181)

<table>
<thead>
<tr>
<th>Time since qualification</th>
<th>%</th>
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<tr>
<td>&gt;15 years</td>
<td>77%</td>
</tr>
<tr>
<td>11-15 years</td>
<td>8%</td>
</tr>
<tr>
<td>6-10 years</td>
<td>12%</td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>3%</td>
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<table>
<thead>
<tr>
<th>Time in MS Practice</th>
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<tbody>
<tr>
<td>&gt; 10 years in MS practice</td>
<td>43%</td>
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## Assessment & Evaluation (n=181)

<table>
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<tr>
<th>Statement</th>
<th>Yes (%)</th>
<th>No (%)</th>
<th>Unsure (%)</th>
</tr>
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<tbody>
<tr>
<td>Sleep management is part of work role</td>
<td>85%</td>
<td>8%</td>
<td>7%</td>
</tr>
<tr>
<td>Use a specific sleep assessment instrument</td>
<td></td>
<td>67%</td>
<td></td>
</tr>
<tr>
<td>Confident with sleep management knowledge</td>
<td></td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>Would value further sleep management training</td>
<td></td>
<td></td>
<td>49%</td>
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</tbody>
</table>

- 35% unaware that specific sleep assessment instruments exist
- Variety assessment instruments used, including:
  - Epworth Sleepiness Scale
  - Visual Analogue Scale
  - Pittsburgh Sleep Diary
# Key Sleep Interventions Used (n=181)

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<tr>
<th>Intervention</th>
<th>Percentage</th>
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<tr>
<td>General verbal advice</td>
<td>81%</td>
</tr>
<tr>
<td>Verbal advice tailored to the individual</td>
<td>74%</td>
</tr>
<tr>
<td>Incorporated within other symptom management</td>
<td>72%</td>
</tr>
<tr>
<td>Within fatigue management/energy conservation programmes</td>
<td>61%</td>
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Discussion

- Provides an initial understanding of what is happening in current UK practice.
- Suggests sleep practice is variable and specific knowledge may be limited.
- Vast majority (85%) of nurses and allied health professionals considered sleep management their role.
- Despite this only 10% were confident in their knowledge of sleep disturbance.
- Only 8% reported confidence in carrying out a sleep assessment.
Discussion and future research

- Verification is required

- Exploration in more depth required:
  - Review current assessments
  - Investigate effectiveness of non-pharmacological sleep interventions in MS
  - Determine knowledge levels about sleep disturbance by therapists and nurses
  - Determine what type of training would be most helpful to increase knowledge and confidence
The Team

Research Team

• Jenny Freeman
• Paula Gardiner
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• Kay McDowall
• Alison Nock
• Ewa Johansson-Charles
• Helen Rowlands

MS Trust Support

• Amy Bowen
• Brenda King

Ethics approval gained from Plymouth University Faculty of Health, Education and Society Ethics Committee, October 2011.