Background

- Motor Neurone Disease (MND), a progressive neurodegenerative condition with no known cause or cure and a typically poor prognosis - average survival from diagnosis stands at approximately 14 months - results in the deaths of over 100,000 people, each year, worldwide.

- Fragmented, poorly communicated and generally dissatisfying service provision add to the already considerable strain experienced by carers of people living with MND (plwMND).

- The challenges of caring for someone approaching death are both varied and extremely demanding and the bereaved are known to have poorer health outcomes than comparable groups of non-bereaved individuals.

- An estimated 10-20% of bereaved people who experience bereavement in a decidedly intense manner – instances where symptoms include difficulty accepting the loss, numbness, bitterness, identity disorientation and a feeling of being stuck in grief - a condition commonly known as ‘Prolonged Grief Disorder’ (PGD).

- Although similarities exist with the experiences of ‘normal’ bereavement, PGD health consequences are typically longer-lasting and more severe. Little attention has been given to this condition in family carers of plwMND.

Aims

1) To investigate the experience and awareness of pre- and post-bereavement support available to family carers of plwMND amongst health and social care professionals;

2) to ascertain health and social care professionals’ experience of PGD amongst this population;

3) to gather views on how health and social care professionals think pre- and post-bereavement support can be improved.

Methods

An online survey of 14 items comprising open and closed questions was administered via Survey Monkey™ software to health and social care professionals in England working with plwMND and/or their carers (n=56). Snowballing was encouraged from those receiving the survey to share the survey link with others. The final sample included respondents from the following professions:

<table>
<thead>
<tr>
<th>Profession</th>
<th>Percentage of respondents</th>
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<tbody>
<tr>
<td>MND Association Regional Care Development Adviser (RCDAs)</td>
<td>21.4%</td>
<td>12</td>
</tr>
<tr>
<td>MND care centre administrator</td>
<td>56.4%</td>
<td>31</td>
</tr>
<tr>
<td>Other</td>
<td>17.9%</td>
<td>10</td>
</tr>
<tr>
<td>No response</td>
<td>5.4%</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>56</td>
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Conclusion

- Survey data reveal that health/social care professionals were uncertain of the most appropriate course of action to pursue to support carers facing bereavement.

- Twenty-three respondents (41.1%) viewed bereavement-related support provided to family carers POST-bereavement as only ‘Poor’ or ‘Fair’ (Fig.1); 24 respondents (45.3%) had encountered family carers of plwMND they considered were experiencing PGD; 3 (69.8%) respondents did not feel able to accurately predict future cases of PGD.

- When asked if they felt that the implementation of a Bereavement Risk Indicator Tool to possibly predict family carers at risk of experiencing PGD would be worthwhile, almost 70% (n=37) responded ‘yes’ (Fig. 2).

- Our data indicate that bereavement-related support for carers of plwMND could be improved, that PGD may be experienced at a higher level in this population and that health/social care professionals face varying challenges in accurately ascertaining the likelihood of PGD amongst MND carers.

- We plan to develop a Bereavement Alert Risk Indicator (BARI) tool for use with family carers of plwMND and other neurodegenerative disorders. This type of system would enable the identification and signposting of those most likely to benefit from any available support and to the most appropriate treatment in a timely manner.

- In conclusion, we propose that such a tool could be help health and social care professionals to identify family carers of plwMND at risk of PGD and that its potential application deserves careful consideration by health care professionals, policy-makers and research funders.

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