**Does a lack of social support and perceived stigma contribute to psychological distress in individuals with motor neurone disease?**

**Aims:** This research aimed to find out if there is a relationship between levels of stigma (a feeling of shame about being different and feeling that you will be treated differently because of this, or actually being treated differently because of this difference) and levels of psychological distress experienced by individuals with motor neurone disease (MND) also known as amyotrophic lateral sclerosis (ALS) and Lou Gehrig disease. The study also aimed to find out the strength of this relationship compared to other important factors such as symptom severity and social support.

**Design:** An online survey method was used. It was expected that people who had greater social support and felt less stigmatised would feel less distressed, even when other factors such as their physical status was taken into account.

**Methods:** Individuals with a diagnosis of MND were recruited internationally through social media and through various organisations and support services for people with MND. The questionnaire for psychological distress assessed depression, anxiety and stress. The questionnaire for stigma assessed felt and enacted stigma; 'felt stigma' refers to a feeling of shame about being different and feeling that discrimination for this difference will occur, whereas 'enacted stigma' refers to actual experience of this discrimination. The social support questionnaire looked at levels of social support an individual receives from a significant other, family and friends.

Seventy-seven participants completed the survey. First data were analysed using correlations (which look at whether an increase or decrease in one variable, like stigma, leads to an increase or decrease in another variable, e.g. depression). Then hierarchical regression analyses were used which look at relationships between all the variables in a statistical model to identify which are the most important. This study assessed whether enacted stigma, felt stigma and social support were all important predictors of distress.

**Results:** Significant correlations were found between social support, felt and enacted stigma and psychological distress. As expected, more social support was associated with less psychological distress and less felt and enacted stigma were associated with less psychological distress.

However, when the variables were put together in a statistical model, the results were more complicated. On its own, felt stigma significantly predicted anxiety, depression and stress over and above other variables and was a more powerful predictor than social support in each of the models (one model for depression, one model for anxiety and one model for stress). This means felt stigma was the most important variable in the models for predicting distress.

Social support significantly predicted anxiety and depression but not for stress when the stigma variables were also included in the model. This means social support is also important, but not as important as felt stigma for predicting distress.

These analyses showed that enacted stigma did not predict psychological distress when in a model with felt stigma and social support, so this variable was the least important when considered alongside felt stigma and social support.

**Conclusions:** The results of this study suggest that individuals with higher levels of social support have lower levels of psychological distress. This indicates that having access to adequate social support can be a protective factor for avoiding psychological distress for individuals with MND.  Therefore, ensuring that people with MND can continue to have contact with friends and family to support them is important.

The results of this study also suggest that individuals with higher levels of felt stigma have higher levels of psychological distress.  This indicates that interventions aimed at reducing felt stigma are important.  This might mean working with individuals to help them feel less stigmatised.  However, we also know that felt stigma and enacted stigma (being discriminated against) are linked.  So, we also need to work in society to remove the discrimination and stigmatising attitudes that people experience, to reduce the felt stigma people experience and therefore reduce their distress.