



ARCBITE



Brokering Innovation Through Evidence

Communicating Wellbeing and Quality of Life in Motor Neurone Disease to Multidisciplinary Teams

Background:

Motor Neurone Disease (MND) is a life limiting neurodegenerative disorder characterised by muscle weakness, fatigue, speech problems and swallowing and breathing impairments. Care for people with MND is provided by Multidisciplinary Teams (MDTs) that comprise of dieticians, physiotherapists, psychologists, occupational therapists, speech and language therapists and assistive technology professionals, to name but a few. These teams work to meet the physical, social and emotional needs of people with MND. Meeting the emotional and psychological needs of people with MND is important for improving their quality of life (QoL).

What was the aim of the project?

To engage community multidisciplinary teams (MDT) working in the Liverpool region in considering wellbeing and quality of life (QoL) issues for people with Motor Neurone Disease (MND)

We had two objectives:

1. To educate clinical staff about psychological and social wellbeing in MND to see if this would change their clinical practice and increase their focus on psychological issues when managing QoL.
2. To gather insights about how communication could be improved amongst staff teams.

What did we do?

- We invited staff from community health and social care across Liverpool to attend a World Café style¹ half-day workshop.
- We asked staff to complete a questionnaire prior to the workshop and two weeks after the workshop, so that we could assess any change in their knowledge about QoL.
- Staff that registered their interest, were also invited to take part in an interview two months after the workshop to talk about their learning from the workshop and their views about QoL in relation to their MND practice.
- During the workshop, talks took place about QoL in MND and the findings of the TONiC study², related to MND presented.

How did we involve people?

Two former MND carers were involved in the development, analysis and dissemination of the study and attended team meetings and workshops hosted by NIHR CLAHRC NWC.

What we found and what does this mean?

- Nineteen clinical staff from a range of disciplines attended the workshop.
- Post-workshop questionnaires showed that 9 out of 10 people had improved their knowledge of QoL.
- Respondents indicated that the workshop had been an opportunity to network and share experiences about managing MND and had increased their understanding of QoL and health inequalities.



- Respondents noted that communication can address QoL, that QoL is different for each person and, that no assumptions should be made about QoL.
- The evaluation of interview data identified five main themes: learning quality of life in MND care, local inequalities in health affecting MND, pathway building and barriers in MND, quality learning in MND and quality care within the MND trajectory.

In conclusion, our workshop, which is one of the first reported methods to address psychological and emotional needs for people living with MND by improving staff communication, was successful in improving knowledge of staff about QoL in MND. This approach was also successful in encouraging discussion of QoL within staff teams.

More detailed findings of this study can be found at:
<https://link.springer.com/article/10.1007/s11136-019-02193-x>

What Next?

The next step will be to implement findings into practice.

Work focusing on improving QoL for people with MND also continued into the third round of the CLAHRC NWC Partner Priority Programme focusing on enhancing QoL by scoping activities that people

with MND could participate in within one local borough. The published findings of this work can be found at:

<https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.13049>

Who was involved?

University of Liverpool, UK; NIHR NWC, Liverpool, UK; Walton Centre NHS Foundation Trust, Liverpool, UK; Motor Neurone Disease Association, Northampton, UK; Faculty of Health and Medicine University of Lancaster, UK.

References:

1. Brown, J. (2005). *The World Café: Shaping our future through conversations that matter* (1st ed.). San Francisco, CA: Berrett-Koehler.
2. Young, C. A., Mills, R. J., Tennant, A., & on behalf of The Tonic Group. (2016). Physical and psychological influences upon quality of life in Motor Neurone Disease/ALS. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 17(S1), 26.

What is NIHR CLAHRC / ARC North West Coast?

The Applied Research Collaboration North West Coast (ARC NWC) superceded CLAHRC NWC in September 2019. It is a partnership between universities, NHS, public, etc.

Its mission is to undertake applied research to improve public health, wellbeing, quality of care & reduce health inequalities across the North West Coast region.

<https://arc-nwc.nihr.ac.uk/>