A person-centred approach to delivering coordinated care to people with Motor Neurone Disease in Bradford

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Introduction

People living with Motor Neurone Disease (MND) often have their care delivered by a high number of professionals. In Bradford and the surrounding district, it was recognised that people living with MND and their families did not have a single point of access for their care. It was felt that this led to poor quality care through poor coordination and inequity in access to services.

Further, there was a lack of dedicated resource to fully support the organisation of the Multi-Disciplinary Team (MDT) clinics. The MDT's Consultant in Palliative Medicine was previously leading on the many aspects of coordination. A need was identified to use resource more effectively by freeing up the time and expertise of this senior clinician.

To address this, the MND Association have funded a MND Care Coordinator post which is based at Marie Curie's hospice in Bradford. This post is currently held by a senior nurse with over 20 years' experience in palliative care. The role has been in place from June 2017 and the post is funded for 15 hours per week. The role is the first of its kind for Marie Curie and for the Bradford area.

Aim

As a new initiative for the area, it was identified that a formative evaluation approach would help to understand how the role works in practice and identify how it could be further shaped to best meet the needs of people with MND and their families and carers.

This poster presents the key themes identified from the data and how they relate to McCormack and McCance's Person-Centered Nursing Framework.[1]

Methods

A mixed method approach was adopted. For the formative evaluation, this included the following methods:

- Semi-structured interviews with the MND coordinator and the Multi-Disciplinary Team lead consultant
- Self-reported MND coordinator time log
- Document analysis (including examples of meeting minutes, feedback from a carer, weekly caseload update)
- Case studies

Person-Centred Nursing Framework

McCormack and McCance describe the Person-Centered Nursing Framework as consisting of the following four constructs[1]:

1. **Prerequisites** – described as the attributes of the nurse
2. **The care environment** – the context in which care is delivered
3. **Person-centered processes** – activities that form overall care delivery
4. **Expected outcomes**

In particular, McCormack and McCance describe how the *prerequisites* and *care environment* elements are required to facilitate and support the latter two constructs.

Findings

The MND coordinator's time log indicated that there were three core activity areas:

- Patient psychological support
- MND MDT clinics
- Coordinating patient care and caseload management

Patient Psychological Support

Given the practical and logistical challenges that may arise for people living with MND and their families, it should be expected that some conversations about care coordination have the potential to be emotive, difficult or challenging.

> **You know if somebody is quite distressed about something not happening and then they [the co-ordinator] said "okay, I will go off and sort it out"**
>
> **And actually what they need is somebody to help them with their stress at the time.**
>
> MND MDT consultant

As the coordinator has substantial experience as a senior nurse, they are therefore skilled and experienced in providing this kind of support. This links directly to the *Prerequisite* construct of the Person-Centred Nursing Framework, of which professional experience and well developed interpersonal skills are specified as core components.

There was also evidence of significant levels of reflective practice, which is emphasised as a key factor of the *Prerequisite* construct. For example, the following quote demonstrates how the coordinator's communication plan was tailored according to patient needs, and also how the coordinator is aware of how their role might be perceived by people with MND and their families:

> **I know that we have young patients at the minute…One patient last week was on half term so I left them last week as they were with their children and they were busy and didn't want constant reminder of their illness. I am very aware of that.**
>
> **There is a fine line between giving the support but not invading a patient's life so that I am always reminding them that they have a terminal illness**
>
> MND coordinator

MND Multidisciplinary Team Clinics

The MND MDT clinic has been established at the Bradford Hospice for many years. This monthly clinic can be considered to fall within the *Care Environment* construct of the framework, as it aims to create a care context where the appropriate professional skills are brought together to facilitate shared decision making.

However, the coordinator has aimed to increase the level of person-centred focus of the MDT. This is in part facilitated by their distinct remit as advocate for people with MND and their families and carers. In turn, this helps to foster increasingly person-centred care

> **I try really hard to say let's talk about the patient's agenda and not ours – in a nice way…I think people are quite glad to hear it. People are responsive to that. I think before there has been nobody there to coordinate or facilitate that.**
>
> MND coordinator

Coordinating Patient Care and Caseload Management

Nearly two-fifths of the coordinator's time is spent on coordinating patient care activities and caseload management. This area of the coordinator's work can be considered to fall into the *Patient-centred process* of the framework, which is described by McCormack and McCance as when the "activities that operationalise person-centred nursing".

Activities in the coordinating patient care category included telephone calls to patients, home visits, hospital visits and organising attendance at day therapy. Meeting patients and carers in person, in their home setting was felt to facilitate identification of further coordination needs.

> **I think there is something very crucial about seeing people at home. Because you get a very different picture about how people are coping… it gives a really true picture of what people are living with really.**
>
> MND MDT consultant

Caseload management was also found to be a key activity for the coordinator. In the MDT consultant interview, it was raised how part of the rationale for the coordinator role was about ensuring that there was a holistic overview of the caseload.

> **We needed the co-ordinator to have an overall handle on the patients all the time. To keep an eye on what is happening with them, because you know in the three months between clinic things can happen**
>
> MND MDT Consultant

Discussion

Findings from this six-month evaluation suggest that the MND coordinator role is currently addressing three of the four constructs with the Person-Centred Nursing Framework.

The foundations of implementing a person-centred approach are contributed to through the coordinator's prerequisite professional experience, interpersonal skills and through the fostering of a person-centred care environment. In turn, this enables the delivery of activities that address the patient need.

Evaluation of patient related outcomes further down the line will aim to demonstrate the extent to which the person-centred approach has had positive impacts for people with MND, their friends and families.

1 McCormack B, McCance TV. Development of a framework for person-centred nursing. Journal of advanced Nursing. 2006 Dec 1;56(5):472-9.

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