Optimisation of services for people with Motor Neurone Disease [MND] in Lancashire and South Cumbria

Executive Summary

compiled by
Dr Mary O’Brien
Bridget Whitehead

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Grant-holders: Prof Douglas Mitchell, Dr Mary O’Brien, Prof Barbara Jack, Pauline Callagher.

Research Assistant: Bridget Whitehead

Additional copies of this report can be obtained from Dr Mary O’Brien at obrienm@edgehill.ac.uk
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1.0 Background

Motor Neurone Disease (MND) is a progressive neurological disease without curative treatment. As a consequence of degeneration of upper and lower motor neurones of the central nervous system (brain and spinal cord), there is progressive wasting and weakness of associated muscles. Those diagnosed with MND suffer inexorably progressive paralysis which may affect limbs, trunk or neck. When the disease occurs in the bulbar region, there is worsening difficulty with speech and swallowing. Respiratory symptoms might occur at onset or in subsequent stages of the disease; death is frequently the result of respiratory failure. Over 50% of those with MND die within 3 years of the onset of their first symptom.

A number of UK government initiatives in recent years have been intended to ensure that the experiences of service users and their carers help to shape the National Health Service (NHS), so that it is as sensitive to the needs of individuals as possible and capable of meeting them as effectively as possible. (DH1997, 1999, 2004, 2005). Spanning these initiatives is the requirement that evaluation of the services is conducted from a service user perspective. This increased emphasis on incorporating service user perspectives in the development and evaluation of health services accompanies calls for greater user participation across health research.

This research study was conducted to enhance and strengthen evidence of service users’ needs, with a distinct focus on the regional provision of health, social and palliative care services. The study aimed to inform the development of more seamless structures for the management of the disease throughout the patient’s journey, including facilitation of end of life choices.

The systematic nature of the disability resulting from MND means that patients become dependent on a wide range of health, social and palliative care services as their condition progresses. MND can thus be viewed as an exemplar condition; people with MND face many of the problems experienced by those with other, less rare neurodegenerative conditions including physical decline and psychological and communication difficulties. However the time frame for those with MND, due to the rapidly progressive nature of the disease, is much more compressed. Health, social and palliative care service provision for MND can
therefore legitimately be offered and utilised as a model for addressing other neurological
and degenerative conditions. MND is often rapidly progressive, so any delay in receipt of
information, care, support or equipment can be catastrophic both for people with MND and
their carers.

The National Service Framework for long term conditions (NSF) (DH2005) emphasised the
centrality of lifelong care for people with MND, particularly a need for integration of care
and joined-up services. It has been recognised that the needs of people diagnosed with
MND, and their carers, have not consistently been met by health, social and palliative care
services, Van Teijlingen et al (2001). Previous studies have revealed a number of difficulties
regarding the provision of services for people with MND and their carers. However, there
remain sizeable gaps in the literature about the personal experience of living with MND that
need to be addressed, especially if services are to be developed in line with the key themes
of the NSF (DH 2005).

Personal narratives are regarded as a useful means to guide the development of services by
taking account of the personal experiences of service users (Overcash, 2003) and this
technique has been employed to gain the insights of patients and carers improving a range
of services, including critical care (Todres et al 2000), palliative care (Turner et al 2000) and
breast cancer (McKinley et al 2001). Previously studies have elicited the personal views of a
small sample of people diagnosed with MND and their carers about their experiences, using
interviews (Hughes et al, 2005; Brown et al, 2006), but methodological limitations are
apparent. Methodological approaches which could address such limitations were clearly
required.

2.0 Methodology

2.1 Research aim

The aim of the study was to explore the personal experiences and perceptions of accessing
health, social and palliative care services by those directly affected by MND (i.e. people with
MND, carers and past carers).
2.2 Research objectives

The study set out to address a number of objectives:

1. To assess the extent to which the changing needs of people living with MND are being met by health, social and palliative care services.
2. To identify interventions which make a difference to people living with MND.
3. To provide information to policy makers on resources required to support those living with MND.
4. To inform the development of a care pathway to guide interventions required to meet the changing needs of people with MND.

2.3 Methods

The study adopted complementary data collection methods incorporating a retrospective case note review and qualitative interviews to gain an understanding of patient and carer experience of services for MND. Such an approach is designed to enable exploration of participants’ experiences, feelings and beliefs (Polit and Beck 2010). It was intended to address limitations within previous studies by incorporating a longitudinal element into the study.

The study had a number of components:

1. A retrospective case note audit of the current MND population in Lancashire and South Cumbria was undertaken
   i) To identify the characteristics of the MND population as a guide to selection of participants for the main part of the study.
   ii) To inform the development of broad ranging topics for inclusion in face to face interviews to elicit the oral histories of those directly affected by MND.

2. A loosely structured tape-recorded interview with people diagnosed with MND and current carers (interviewed separately wherever possible) was used to obtain the personal narratives of the effects of living with MND.

3. A longitudinal element to the study was open to these participants to record their experiences over time through a variety of diary options or interviews on a 3 monthly basis for a period of up to 12 months.
4. One-off loosely structured interviews were conducted with past family carers to obtain their personal narratives. These participants provided an invaluable source of information on personal experiences having lived through the entire MND journey from pre-diagnosis through to post bereavement.

3.0 Audit

A comprehensive case note review of all patients (n=97) being followed up by Preston MND Care and Research Centre was undertaken at two time points: Time 1 (T1) (March 2008) and Time 2 (T2) (March 2009). Data were collected regarding the personal demographic characteristics of the patient population, including site/type of disease onset. Current disease severity was assessed using two recognised measures, the ALS Health States Scale (ALS-HSS) (Riviere et al 1998) and the revised version of the ALS Functional Rating Scale (ALSFRS-R) (Cedarbaum et al 1999). The ALS-HSS is a clinical classification system for patients with MND which classifies patients into one of four health states ranging from state 1 (mild) to state 4 (terminal): the ALSFRS-R is a 12-item scale, which measures functional status and disease related disability in people with MND with items rated from 0 (cannot do) to 4 (normal ability) with a maximum total score of 48. Level of uptake of gastrostomy feeding (PEG), non-invasive ventilation (NIV) and aids/equipment, level and type of care required, time from disease onset to diagnosis and the time from diagnosis to nurse specialist follow-up were also recorded. Data were stored and analysed using SPSS 16™.

4.0 QUALITATIVE STUDY

4.1 Participants

Participants were in the main recruited through their contact with the Preston MND Care and Research Centre. The Centre receives in the region of 30 new referrals each year and provides regular follow up for over 80 patients at any one time. Local branches of the MND Association were also approached and appropriate voluntary sector newsletters aimed at the MND community were utilised to inform past carers of the nature of the study and to aid recruitment. Maximum variation purposive sampling, guided by the four health states of ALS-HSS, was employed when selecting people with MND for inclusion. A geographical element to recruitment was incorporated by purposively selecting participants from across the PCTs served by the MND Care and Research Centre in order to capture a broad range of
experiences. 24 people with MND and 18 lay carers were recruited. 10 past carers of people who had died of MND were also recruited into the study.

4.2 Data collection

Interviews comprised loosely structured, in-depth explorations of the personal experiences of the period leading up to, at, and following diagnosis. The loosely guided interviews allowed participants to elaborate on incidents and issues of importance to them. They included the exploration of individual experiences of accessing services and sought views on the standard, level and availability of health, social and palliative care services together with identification of what was important to people with MND and their carers. The location of the interview needed to be one with which the participant was comfortable, able to access any support or treatment required, and where privacy was ensured. Therefore all the interviews were conducted in the participants’ homes. It was also hoped that this would encourage the development of a rapport between the interviewer and the participant. A number of participants experienced speech impairments as a result of the disease; in order to ensure these participants were able to participate they were offered alternative means to carry out the interview e.g. via email.

All patients and current carers were offered the opportunity to continue into a longitudinal study with the collection of narratives of their on-going experiences. Fourteen people with MND and one carer agreed to complete a diary for a period of up to one year allowing the researchers to understand how services were responding to their changing needs as the illness progressed. To ensure inclusivity of all participants, despite the range and level of disability, they were offered an assortment of options to record their diaries including handwritten, computer, dictaphone, and follow up interviews. Interviews were digitally recorded and all material, including diary entries, was transcribed verbatim.

4.3 Analysis

A thematic analysis framework was used to analyse the data. A number of interview and diary transcripts were returned to participants for verification to ensure accurate representation of their views. All transcripts were then read through carefully a number of times noting any comments of interest in order to develop an overall impression of the
content; areas of commonality between transcripts were noted as potential themes. Following identification of shared themes, relevant extracts from the transcripts, which supported the themes, were identified. QSR Nvivo, a computerised data analysis tool assisted in the management of the analysis. To establish an element of rigour and reduce the likelihood of introducing bias at the analysis stage, three researchers independently analysed the same three transcripts before comparing and agreeing on initial codes.

4.4 Ethical approval
The study was granted ethical approval by the North Manchester Local Research Ethics Committee; R&D approval was from Lancashire Teaching Hospitals NHS Foundation Trust and throughout the study adhered to research and governance requirements.

5.0 Summary of Findings
The findings of this study significantly augment our understanding of the experience of service use for people living with MND, and their carers. Previous research in this area has tended to be quantitative and relied heavily on questionnaires and scales (Leigh et al, 2003; Miller et al, 2010; Van den Berg, 2005; Traynor et al, 2003; Chio et al, 2006; Oliver and Webb, 2000). There have been a small number of studies which explore the experiences of health and social service provision of individuals with MND and their carers using qualitative approaches; moreover a significant paucity of research studies using longitudinal qualitative methods severely limits our insight into experiences over time. According to Brown et al (2006) the perspectives of people with motor neurone disease and their carers are rarely reported in research studies. The study revealed a mix of experiences of services, with a number of issues arising at certain stages of the disease trajectory. This study has implications for all health, social and palliative care professionals working with people with MND and their families.

5.1 Diagnosis
Limited knowledge and understanding of MND amongst GPs led to delays in primary care; participants frequently reported doctors’ failure to recognise the signs and symptoms of the disease. Problems in secondary care services were also apparent, with extended waiting times for investigations resulting in further delays in arriving at a diagnosis. A need for a
more streamlined diagnostic pathway for patients with MND, if they are to receive the specialist help and support they require in a timely fashion is evident from this study.

The diagnostic experience itself was often criticised by patients and carers. A number of this group felt there was a need for improved communication with consultants delivering the diagnosis; some felt a lack of sensitivity and found there had been inadequate time allowed for patients and carers to ask questions. These experiences frequently had a negative impact on subsequent patient-health professional relationships. In addition, a number of participants in this current study reported wanting better guidance particularly direction towards support services at this stage. Many patients and carers recalled experiencing a lack of emotional support at this stage and some highlighted a particular need for counselling and psychological services at the time of the diagnosis. These findings support the work of McCluskey et al (2004), Johnston et al (1996), Borasio et al (1998) and Hugel et al (2006).

5.2 Post diagnosis – Immediate

There is a need for professionals to ascertain how much information the patient and family carers require following diagnosis, and for this to be monitored over the course of the disease. Family carers requiring diverse information often reported they were not given the information they required to make them capable of anticipating the patient’s future needs. As a consequence, it can be argued that a discrete consultation with family carers following diagnosis would be beneficial to them, as it could allow them to discuss their anxieties and concerns without upsetting the patient.

A number of people reported positive experiences of the multi-disciplinary team (MDT) when they were invited to join with professionals in this group context. Patients and carers appreciated being involved in consultations about decision-making. However, issues regarding delays with the provision of equipment and adaptations were frequent, items were often supplied too late to be of use to patients, as has been reported elsewhere (van Teijlingen et al 2001; Robinson and Hunter 1998). Furthermore, patients and carers reported the process of applying for financial benefits as too complicated with a detrimental impact on their lives through increased stress. Arranging care packages was often reported as being problematic; some patients and carers felt they were not given adequate
information or signposting to relevant agencies resulting in delays. It was apparent from comments received that health care and social services lack thorough integration.

5.3 Post diagnosis – mid stage
This study confirms the claim made previously, that caring for someone with MND increases the responsibilities of, and distress in, carers (Ray and Street 2005; Love et al 2005; Ray and Street 2007) and supports the claim by Mockford et al (2006) that carers often find that their needs are not adequately being met by services. Although carers were often appreciative of information and support offered by health professionals, some felt they were being expected to use equipment to attend to the nursing needs of their partner with insufficient training or information. Despite being regarded as highly valuable sources of support by carers, a number reported difficulties accessing respite services; moreover reaction to care agency staff was frequently to consider them lacking adequate training and knowledge of MND, which could heighten the sense of burden and anxiety in carers. The importance of having nurse-led care agencies and improved training for paid care staff was highlighted by a number of individuals during interviews. Many carers also reported a need for emotional support or counselling to be available to them.

5.4 Post diagnosis - late stage
In the later stages of the disease, support provided by Specialist Palliative Care Nurses was deemed as especially beneficial. It is however apparent that access to these services was not universal, endorsing the findings of Oliver and Webb (2000). Additionally, a need for earlier and greater involvement in patient care from district nurses and GPs has been highlighted in this study. This finding is in accordance with the End of Life Care Strategy (2008) which acknowledges the need to improve end of life care for all patients including those with non-malignant diseases.

5.5 Death and Dying
A number of past carers interviewed described needing counselling and support following the bereavement of their partner, reporting a sense of being abandoned by services once the care and treatment of the patient had ceased. Those who had accessed counselling or support from organisations were very positive about their experiences. These findings
support the work of those who found that the experience of MND had a lasting emotional impact on family members following bereavement and suggest that MND clinics, organisations, and healthcare systems could have a greater role in meeting their needs. Martin and Turnbull (2001), Hebert et al (2005) (Leigh et al 2003; Howard and Orrell 2002).

5.6 All stages
Patients and carers cited a perceived lack of continuity in services and at times a sense of abandonment without adequate specialist support. This corroborated a number of similar findings by other studies in this area (Brown et al 2006; Jarrett et al 1999; Mockford et al, 2006; Kristjanson and Oldham, 2005; Hocking et al, 2006).

There were numerous comments regarding poor understanding of the complex needs of people with MND amongst health and social care professionals and social services care staff. A greater knowledge and awareness of MND amongst these groups is necessary to ensure that patients and carers receive accurate advice and good standards of specialist treatment in accordance with the guidelines set out in the National Service Framework (DH2005). This has resonance with findings elsewhere (Hughes et al, 2005; Hocking et al, 2006).

A number of key outcomes from the study have clear implications for practice namely;

- diagnostic delays,
- poor diagnostic experience,
- confusion regarding the involvement and responsibilities of members of the MDT,
- continuity and communication issues within the MDT,
- low service update due to uncertainty over entitlement
- poor integration with social care services and poor understanding of the complex needs of people with MND and their carers.

6.0 Recommendations
A range of interventions intended to optimise the service provided for people with MND in Lancashire and South Cumbria have been identified in the study. These interventions are evidence-based, having been shaped to the specific problems identified during the study.
Once established and tested in this area, these interventions could be used to benefit patients elsewhere.

- More precise information is needed about when, how and why delays occur within primary and secondary care to enable the development of improved services.
- There is a need to ensure that accepted guidelines for the delivery of the diagnosis in MND are adhered to within practice. It is imperative that discussions immediately following diagnosis should focus on providing contacts and support networks for the patient and the family. Therefore a communication of the diagnosis care pathway is to be developed with local practitioners and service users. This will be introduced into routine practice for the telling of the diagnosis of MND in Lancashire and South Cumbria within 12 months of the completion of the study. There may be issues regarding the need for communication skills training for some medical staff which would have to be overcome.
- In order to aid clarity regarding roles and responsibilities of health and social professionals, a patient-held communication file with details of all professionals likely to be involved with the patient’s care will be developed. A key worker will be identified to act as a point of contact for patient/carer and other professionals involved with the patient. This should better inform patients and carers regarding the services involved in their care and communication between professionals and agencies would be improved. Incorporation of this suggestion into routine practice within 12 months of the completion of the study would ensure that the various agencies involved in the patients’ care were working co-operatively.
- Health and social care services lacked integration and patients/carers were often unsure of care service entitlement and how to organise care packages which affected the uptake of social services care. The inclusion of a social worker on the MDT, who could be present at MND clinics, is viewed as a means of ensuring greater integration of these services and a way of
informing patients of their service entitlements from diagnosis. The feasibility of implementing such a service will be explored with the relevant departments.

- It is apparent that inconsistencies are to be found within the current system and a need exists for positive aspects to identified and set the standard throughout the provision. Care pathways are to be developed by local practitioners and service users, to guide health, social and palliative care professionals and care staff, and to be implemented within two years of completion of the study, whilst covering the entire period from diagnosis through to bereavement support, will be instrumental in meeting this aim.

- Poor understanding in some health, social and palliative care professionals and care staff, of the complex physical and psychosocial needs of people with MND and their carers, was evident. There is an evident and pressing need for further education and training to be provided for these groups, to improve the care for people with MND. A programme of on-line educational materials are under development and the MND Association have produced a range of educational materials; it is recommended that links to these are provided by the MND Nurse Specialists when referring people with MND for services as a means of facilitating greater understanding of the management of the illness.

7.0 Conclusion & Further Research

Patients and carers reported that certain aspects of the care they received were extremely beneficial, including co-ordinated care, knowledgeable staff, the specialist MND clinic, forward planning, emotional and psychological support, pro-active health and social care staff, and information provision appropriate to needs. However, it also appears from the study, that the various and changing needs of patients and carers are not always met by the health, social and palliative care services. In order to meet these needs there are a number of changes that should be made to current services.

There is a need for greater anticipatory planning from all professionals involved in the care of people with MND as well as more timely provision of equipment, adaptations and care services. It is critical that all professionals involved in MND care are enabled to increase
their awareness of patients’ complex social, physical and psychological needs. Patients and carers require further clarity regarding the roles and responsibilities of the multi-disciplinary team as well as simpler, more coherent signposting towards appropriate services and information. The involvement of palliative care services should occur from diagnosis.

The study advocates the use of a number of strategies to support people with MND and their carers which have been outlined. The findings of this study will be utilised to inform the development of a number of care pathways to address the issues raised by patients and carers. These pathways will be based on research evidence and current clinical guidelines and comprise structured plans for delivering the diagnosis and the provision of care in the post-diagnosis phase. It is intended that these pathways will be used by all professionals to promote optimal clinical practice and decision-making in the care of people with MND.

A number of factors within primary and secondary care contributed to delays in arriving at a diagnosis but more precise information is needed about when, how and why these delays occur to enable the development of improved services. This is the subject of a proposed study currently under review by the RfPB programme.

Whilst this study has explored service provision from the perspectives of people with MND and family carers, it has not sought to explore the experiences of health, social and palliative care professionals and care staff who provide these services. These perspectives would complement the findings of the current study, whilst augmenting our understanding of the obstacles to effective treatment of people with MND and their carers.