Background: People with MND can experience a number of hospital admissions throughout the course of their illness. These may be planned admissions for specific interventions or emergency hospitalisation as a result of the development of concomitant illness or advancement of their condition.

Objectives: The aim of this study was to explore experiences of hospitalisation following a diagnosis of MND from the perspective of family carers of people diagnosed with the illness.

Methods: The study reports on a secondary analysis of pre-existing data from two previously published qualitative studies conducted separately by the authors in Northwest England (1;2). Experience of hospitalisation were evident in both data sets but was not the primary focus of the original studies. Only interview transcripts that featured experiences of hospitalisation were included in the secondary analysis; the pooled sample therefore consisted of 10/11 bereaved carers from study 1 and 10/10 bereaved carers together with 3/18 current carers from study 2.

Results: This study identified many negative experiences for MND patients during hospital admission. Lack of knowledge of MND amongst hospital staff was reported by over 50% of respondents and was a cause of frustration and anger amongst carers, which could lead to complaints and conflict with staff.

“‘The consultant who came to look at him admitted to both of us that he didn’t know much about the disease’” (ID304)

“It’s almost like we have had to train people. On that ward, we have to keep pointing things out to them, erm, and it gets, it makes you angry” (ID215)

In some cases this lack of knowledge led to carers spending long periods of time in hospital with the patient to ensure appropriate care was given, but also acting as experts educating nursing staff as to how to care for the MND patient.

“They didn’t know how to deal with her. I had, I had, I can’t believe I had to show the nurse how to feed her with her PEG” (ID305/7)

However some respondents did acknowledge the rarity of the disease, pressures on staff and their need for training. Satisfaction with care appeared to be greater for planned admissions to the neurology ward compared with emergency admissions to the medical assessment unit and it was felt that there should be more specialist beds available.

“The system doesn’t cater for special cases, or it doesn’t seem to cater for special cases. If you get to the right ward, yes, that’s fine but it’s getting to that ward, that’s the problem and when you go in, in an ambulance, you automatically go in an assessment ward.” (ID305/7)

Perhaps less understandable was the lack of basic care as perceived by a significant number of respondents.

“It was filthy… he didn’t have a wash or a shave, erm for two days, he couldn’t help himself, couldn’t do anything for himself until I went at visiting time the day after and gave him a wash and shave, it wasn’t how you would want your loved one to be looked after” (ID306)

Respondents reported lack of attention to the basics such as washing and feeding. There were also complaints about communication with health care professionals, some of whom were felt to be inflexible with regard to patient’s wishes and preferences.

“one of the doctors who came out spoke to him as though he was deaf, shouting at him… didn’t realise that because he couldn’t talk… they seemed to think he couldn’t, couldn’t speak and that..” (ID308)

“‘No’ every answer was ‘no’ they couldn’t do it and I was trying to make sure X’s wishes were respected but it was a waste of time really, the hospital staff they had their own agenda and err, that agenda didn’t agree with ours so ours went out of the window.” (ID6)

Many patients had lost the ability to speak at the time of admission but there appeared to be little attempt to enhance their ability to communicate, with relatives often having to act as patient advocate. Patients were described as feeling frustrated, abandoned and alone, and in a few cases scared of some nursing staff. It is therefore not surprising that some relatives and patients expressed reluctance for admission.

“They shoved her in a side room in Medical Admissions and nobody bothered with her, you know, because she couldn’t communicate and err, because she had a pad there and everything but nobody, you know, they just left her and that put her off hospitals altogether, this hospital anyway” (ID10)

Several patients died in hospital and a negative experience during this final admission impacted on final memories and bereavement.

“the last 3 weeks of me mothers life and they made it terrible absolutely terrible well it was horrific. Well I’m mean I’m not saying everybody at the hospital but… they just didn’t know how to treat her and I think that was the frustrating thing about it” (ID1)

“The last few days they’ll haunt me for the rest of my life and the thing that pisses me off it could have been prevented if people had done their job properly and made a effort” (ID6)

Conclusion: This study has revealed experiences of in-patient hospital care received subsequent to a diagnosis of MND. Although several respondents reported positive experiences during hospital admission, this study highlights that the MND patients, in this sample, have specialist needs which cannot always be met during hospital admission, particularly to non-specialist units. This highlights a need for further training and enhanced awareness amongst healthcare professionals. Not only will this improve care received by the patient at a very difficult time but may also have a lasting legacy for the bereaved.

References: