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Running out of time: The experience of living with a neurological condition

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Statement of the Problem: Adults diagnosed with motor neuron disease (MND) and similar neurological conditions face a time-limited future with few treatment options and no cure. Their experience of receiving a diagnosis is distressing, even when given well. Distress is exacerbated by waiting times, notions of illegitimacy, progressive and frightening symptoms.

Method: This paper draws on a number of studies, using phenomenological qualitative interviews of over 50 families (around 10% of families who live with MND in Scotland) since 2011. The research draws on the social model of disability, to determine barriers to being and doing are constructed for participants and what can be done to remove them. It will reflect particularly on experiences of diagnosis and use Bury's notion of biographical disruption to examine the impact of this on identity. Further this paper will draw on a recent evaluation of the Speak Unique project (voice-banking and restoration to produce personalized voices) and the value of participating in medical research.

Findings: The families who participated unanimously reported difficult experiences of diagnosis. Many struggled to have symptoms taken seriously, to access neurological services, most waited over a year to be diagnosed, many felt consultants avoided a diagnosis and some felt abandoned following diagnosis. In contrast, participants who were taken seriously, with a shorter wait to diagnosis (<6 months) and met with a neurological nurse around the time of diagnosis, were less disrupted. Being aware of and involved in research opportunities gave participants a sense of doing that enabled a recovery of identity.

Conclusion & Significance: Professionals working with and for, adults with neurological conditions, particularly MND, are fully aware of the brutality of these conditions. This paper contributes to wider understandings of how families cope outside of medicalized spaces and what support they need, above what is currently available.



Recent Publications

1. Ferrie J and Wiseman P (2016) Running out of time: exploring the concept of waiting for people with motor neurone disease. *Time and Society* DOI: 10.1177/0961463X16656854.
2. Ferrie J and Watson N (2015) The psycho-social impact of impairment: the case of motor neuron disease. (Ed) Shakespeare T *Disability Research Today*.
3. Ferrie J and Hosie A (2018) Methodological challenges in developing an evidence base and realizing rights. *International Journal of Human Rights* DOI: 10.1080/13642987.2017.1390300
4. Bury M (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness* 4(2):167-82.

Biography

Jo Ferrie is a Sociologist based at the University of Glasgow. She has worked in the Disability Studies field for 15 years, examining the socially constructed barriers that turn impairment into disability, with the aim of removing these barriers. In 2013, she has published the largest global qualitative study of the experience of living with motor neuron disease with Philly Robertson-Reick and Nick Watson. She joined the Euan MacDonald Centre as a PI in 2012 and worked on a number of projects with them, MND Scotland and the Anne Rowling Clinic to further understand the impact of neurological conditions on people and their families. She is also the Director of Glasgow Q-Step (a £3 million centre to create a step change in how social science graduates use and understand quantitative data) and is seconded to the University of Edinburgh as Deputy Director-Training of the Scottish Graduate School of Social Sciences.

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