A delicate Equilibrium: Living with Huntington’s Disease

Date: 5th March 2014
Time: 12.30 – 1.30pm (refreshments will be provided)
Speaker: Dr Eleanor Wilson from Nottingham University
Venue: Edith Cavell Building, Room 01.01 Lecture Theatre
Enquiries/ Parking: Gilly Thomas-Wright (g.thomas-wright@uea.ac.uk)/01603

Background: People with Huntington’s disease (HD) can be affected by motor, cognitive and behavioural symptoms. The length of the illness trajectory can result in patients receiving care at home for extended periods during which the contribution from family caregivers is invaluable. There has been little research into patient or carer perspectives on needs or how these should be met, and how these correspond to professional viewpoints.

Objectives: To gain an understanding of living with, caring for and working in the field of HD.

Study design: A collective case study approach was used to gather data from the person with HD, their family carer and a nominated healthcare professional to build 15 cases involving 33 individuals and 115 interactions (68 interviews and 47 observations) over three years of study participation.

Findings: Living with HD requires continued readjustment to maintain balance between increasing disability, diminishing cognition and living well at home. Patients and carers were challenged to cope with: the diagnosis; an impulse to secrecy and a duty to share knowledge; autonomy and decision making; the transformation of homes to hospitals; and a shift in the burden of care when the patient moved to a residential care home. Examination of services showed how multidisciplinary working, a keyworker approach, disease, person and service specific knowledge alongside continuity of staffing contribute to quality care.

Conclusion: This is the first qualitative study of living with HD incorporating multiple perspectives over time. It explored the complexity of living with HD and the ways in which care can be provided in the community. The study identified a number of daily challenges for both family and professional carers when changes in capacity occur slowly over time. Holistic, multidisciplinary and flexible care is shown to be essential for those trying to balance the delicate equilibrium of living with HD.

Biography
Eleanor Wilson is a research fellow in the Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care in the School of Health Sciences at the University of Nottingham. She is an experienced qualitative researcher and has worked on a range of projects investigating patient and family experiences of illness, staff roles and service evaluations. Her PhD work explored the needs of those affected by Huntington’s disease and the healthcare staff who provide their care. Currently Eleanor is working on an NIHR funded study to explore the use of advance care planning in the community setting. She has also just completed a Marie Curie Cancer Care funded study on ‘Nurses roles in the use of anticipatory prescriptions’.

Our next seminars are:

12th March 2014 12.30pm Shawn Walker, PhD Student, School of Nursing Sciences
‘The development competence and expertise in the practice of upright vaginal breech birth’

19th March 2014 12.00pm Dr Katherine Deane, Senior Lecturer, School of Nursing Sciences
‘How to support nurses to deliver compassionate care – the role of positive practice environments’.

Both to be held in the Edith Cavell Building Lecture Theatre (Room 01.01)

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