Concurrent session 6

Thursday 26 March 2009

Theme: Parkinsons Disease

6.1.1

Palliative care for people with Parkinson's Disease and their carers

George Kernohan, School of Nursing. Faculty of Life & Health Science, University of Ulster, Jordanstown, UK

Co-authors: Felicity Hasson; Mary Waldron; Barbara Cochrane; Dorry McLaughlin; Sue Foster; Helen Chambers; Marian McLaughlin

wg.kernohan@ulster.ac.uk

Abstract:

Background: Whilst management of Parkinson's disease (PD) patients is primarily aimed at preserving life expectancy and limited motor disabilities (Behari et al 2005), a palliative care approach in management of such conditions has been advocated (DH, 2005). However, research suggests that palliative care services are often fragmented and inaccessible resulting in poor quality care for people with advanced PD. (Thompson & MacMahon 2004a).

Aims: To explore experiences, palliative care needs and gaps in service provision from the perspective of the person with PD.

Methods: Exploratory research design using a qualitative approach. Individual semi structured interviews with 54 participants. Data subjected to thematic content analysis.

Results: The participants' reported varied diagnostic experience. Most had little prior PD knowledge. Some felt there was limited subsequent signposting to services. PD placed a physical, psychological and social toll on participants due to loss of mobility and independence, with increasing dependency on informal carers highlighted. Whilst most appreciated their medical provision, their experience of medication relief and service delivery was mixed. Some also referred to a lack of information on financial and social support networks. Palliative care was generally perceived as related to cancer and terminal care. Participants coped with PD by adopting a positive outlook, despite some anxiety about PD's rate of progression. They appreciated the information, advice and supportive role of the PD Society.

Discussion: This study highlights the varied experience of people with PD suggesting some evidence of unmet palliative care need for people with PD and fragmented available services. There was also variation in the levels of clinical and social care support and information signposting among participants.

Conclusions: Although this was a small scale exploratory investigation, involving one time-point, it lends support to the development of a proactive integrative palliative care services approach to address the needs of people with PD.

Recommended reading:

Behari, M., Srivastava, A. & Pandey, R. (2005). Quality of Life in Patients with Parkinson's Disease. Parkinsonism and Related Disorders 11, 221-226

Department of Health (2005). The National Service Framework for Long-term Conditions, London, DH. Department of Health (2005)

Thomas, S. & MacMahon, D. (2004a). Parkinson's Disease, Palliative Care and Older People: Part 1. Nursing Older People 16(1), 22-6

6.1.2

'Bridging' as a constructivist grounded theory of adjustment and coping through late-stage Parkinson's disease: A longitudinal study

Sion Williams, School of Healthcare Sciences, Bangor University, Bangor, UK

Co-author: John Keady

hss042@bangor.ac.uk

Abstract:

Aims: This presentation will explore the experiences of older people (over 60 years) with late-stage Parkinson's disease (PD) and attempts to understand the transitions involved in living with a degenerative neurological condition. The study adopted a longitudinal design which has resulted in 70 collaborative research interviews with 13 people with PD and their carer over an 18-month period.

Methods: Constructivist grounded theory was the main methodological approach in the study (Charmaz, 2000). The search for mutually generated knowledge between the person with PD and the researcher was augmented by centre-stage storyline generation (Keady and Williams, 2007), a process that visually identifies and locates subjective experience. Interviews were the primary source of data collection and the paper will presented findings from interviews conducted between June 2007 and October 2008.

Analysis: This paper reports on 70 interviews with 13 people with late-stage PD and their family carers who were recruited from the caseload of two specialist Parkinson's disease nurses working in North Wales and one Consultant Geriatrician. All participants were diagnosed with late-stage idiopathic PD.

Results: From this collaborative approach, 'bridging' emerged as the centre-stage storyline related to life with late-stage PD. Bridging itself consisted of 4 categories: 'Building on the Past' (1); 'Bridging the Present' (2); 'Broaching collapse' (3) and 'Coming to terms' (4). These categories were underpinned by a number of supporting properties that have important implications for the understanding of late-stage PD and informing the development of the nursing role in providing appropriate and tailored supportive interventions.

Recommendations: The strategies used to 'bridge' provide new insights into the experiences of living with, and creating meaning in, late stage PD. As the presentation will highlight, the importance of biography and gaining 'insider experiences' of people living with PD and their carers are crucial if person-centred services are to emerge.

Recommended reading:

Charmaz, K. (2000). Grounded Theory: Objectivist and Constructivist Methods. In: N.K. Denzin and T.S. Lincoln (Eds.). Handbook of Qualitative Research. 2nd Edition. Thousands Oaks: Sage. Pp. 509-535

Keady, J. and Williams, S. (2007) Co-constructed inquiry: A New Approach to Generating, Disseminating and Discovering Knowledge in Qualitative Research. Quality in Ageing, 8(2): 27-36

Theme: Long term conditions/patient experience

6.2.1

Hereditary Haemochromatosis: The lived experience

Elizabeth O Connell, Nursing Studies, University College Cork, Ireland

Co-author: Orla Sheahan

l.oconnell@ucc.ie

Abstract:

Background: Hereditary Haemochromatosis (HH) is one of the most common hereditary disorders (British Haemochromatosis Society, 2008) resulting in excessive intestinal iron absorption, which is then stored in the liver, pancreas, heart and joints resulting in organ damage and impaired function (Adams & Barton, 2007). Recent surveys have shown that the risk of hereditary haemochromatosis amongst people of Northern European origin is 1 in 400. However, little is known about the experiences, needs and expertise of those living with this disorder.

Aims: To explore the experiences of patients living with HH.

Methodology: A descriptive, qualitative approach was used to conduct this study. Purposive sampling led to the recruitment of 13 participants who were attending a clinic for venesection in a large teaching hospital. Data were collected using in depth interviews and were analysed using Colaizzi's Framework.

Results: The main themes emerging from the data was that of stoic acceptance of a lifelong condition, the search for information about this condition, along with the challenge of managing symptoms and complying with treatment regimes.

Discussion: Patients had very little knowledge about this disease and their need for clear concise information was asserted. In particular, patients identified their need for specific dietary guidelines and education about symptom management. Venesection was identified as a frightening experience for many patients.