

Mixed Perceptions of Palliative Care in Parkinson's Disease



Parkinson's
Disease Society

Research Team



**Prof George Kernohan
(University of Ulster)**

**Dr Barbara Cochrane
(NI Hospice)**

**Felicity Hasson,
(University of Ulster)**

**Helen Chambers
(NI Hospice)**

**Mary Waldron,
(University of Ulster)**

**Sue Foster
(joint appointment)**

**Dr Marian McLaughlin,
(University of Ulster)**

**Dorry McLaughlin,
(joint appointment)**

- **Palliative Care** has been viewed as end-of-life care (Parkinson Disease Society, 2005) and is often identified with Hospice care and cancer care;
- Dept of Health stated: palliative care services should be extended to all who need them, whatever their diagnosis, in the UK (DH, 2005);
- Palliative care requirements should be considered throughout all phases of chronic illness (National Collaborating Centre for Chronic Conditions, 2006).

- **is a chronic progressive neurological disorder;**
- **has some issues similar to those of people with other advanced conditions (Hudson, 2006);**
- **suffer unmet palliative care needs, such as lack of information, ad-hoc delivery of services and a lack of preparation for the advanced symptoms of disease (Goy et al, 2008; Giles & Miyasaki 2009).**

to explore the experiences, palliative care needs and issues at the end of life from the perspective of the person with Parkinson's disease (PD) and their carers

Qualitative, Exploratory Study, including

- review of research relating to PD and Palliative Care;
- one to one interviews with people with PD and those who care/cared for someone with PD;
- thematic content analysis.

Samples of Participants

AGE GROUP	45-54	55-65	65+	Total
Patient	7	18	29	54
Active Carer	5	8	13	26
Former Carer	0	5	10	15
Total	12	31	52	95

Participants

GENDER	Male	Female	Total
Patient	30	24	54
Active Carer	9	17	26
Former Carer	4	11	15
Total	43	52	95

- **Three quarters (n=42) had ups and downs and (n=38) had time when they felt depressed;**
- **Nearly half (n=26) needed help with daily living and (n=44) said their walking was unsteady;**
- **A third (n=18) said their medication was not helping as much as before and (n=21) had swallowing difficulties.**

- All (n=26) provided care for a spouse or partner at home with (n=25) living with a spouse or partner;
- Most participants (n=24) felt their spouses needed help with daily living and that their walking was unsteady and (n=22) said there were times when they felt depressed;
- Nearly four fifths (n=20) felt their spouse had ups and downs and half (n=13) felt their spouses had swallowing difficulties;
- The duration of caring role was over 5 years.

Views on Hospice and Palliative Care

- **Negative Perceptions;**
- **Palliative Care seen as End of Life/
Terminal Care;**
- **Palliative Care linked with Cancer.**

- Many not sure as to what services are available in terms of Palliative Care;
- Did not recall any experience of palliative care;
- Not sure of the appropriateness of palliative care in the care of people with PD.

It [NIH day centre) probably would be good for some people but I don't know if it would be good for B. He is a good mixer and talks to people but he might feel he is getting worse if he goes to a day care centre (P32)

- Perception that palliative care was not currently needed;
- Perception that palliative care might be needed in the future;

I don't know if (hospice) would appeal to either of us. If we need them certainly, we will use it, if we can, but we would like to stay at home both of us as long as we can. (P73)

- **Majority of participants were aware of Northern Ireland Hospice;**
- **Associated services with terminal and end of life care;**
- **Not aware that it provided other care services.**

- *I only thought they did for cancer actually. I don't know. I understood the Hospice was a cancer place (P28)*
- *When people are dying, that's where they go basically, that's it (P19)*
- *Well to me, I know, like a lot of people ,that the Hospice is the end (P82)*

Patient and Carers had mixed perceptions and a lack of knowledge of Palliative Care;

Negative attitudes towards Palliative Care may discourage both patients and carers from seeking or accepting referrals to palliative care services until the patients' condition is very advanced;

Although this was a limited scale investigation, involving one time-point, it raises issues for further research into this area, e.g. Reassuring patients and carers that they can 'dip in and out' of Palliative Care Service Provision.

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www.nice.org.uk

Thank you!

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