

# Pain in PD: Why it matters and why we ignore it

Richard J Davenport  
Edinburgh

# Why does pain matter (1)?

- Long recognised
  - 1817: “rheumatic pain”
  - 1888: Gowers
  - 1986: almost 50% patients with PD had pain
- How common?
  - Huge variability (40-85%)
  - Probably due to methodological issues
  - Chronic pain surprisingly common in GP

**TABLE 2. Prevalence of Pain in PD**

Study Type	Pain Type	Study	PD Sample Size	Prevalence (%)	
Controlled studies	All pain types	Ehrt et al. (2009) <sup>52</sup>	227	67 PD versus 39 controls	
		Defazio et al. (2008) <sup>10</sup>	402	69.9 PD versus 62.8 controls	
		Negre-Pages et al. (2008) <sup>12</sup>	450	61.8 PD chronic pain; twice more frequent in PD than in patients without PD	
		Chaudhuri et al. (2006) <sup>48</sup>	123	27.6 PD versus 30.2 controls	
		Quittenbaum and Grahn (2004) <sup>47</sup>	57	68.4 PD pain in past month; similar to control	
		Shoulder pain	Madden and Hall (2010) <sup>23</sup>	25	80 PD versus 40 controls
		Back pain	Broetz et al. (2007) <sup>49</sup>	101	74 PD versus 24 controls
			Etchepare et al. (2006) <sup>93</sup>	104	59.6 PD versus 23 controls
		Sensory symptoms	Snider et al. (1976) <sup>94</sup>	101	43 PD versus 8 controls
		Uncontrolled studies	All pain types	Hanagasi et al. (2011) <sup>55</sup>	96
Santos-Garcia et al. (2011) <sup>53</sup>	159			72.3	
Chaudhuri et al. (2010) <sup>7</sup>	242			45.9	
Beiske et al. (2009) <sup>21</sup>	176			83	
Martinez-Martin et al. (2007) <sup>95</sup>	545			28.8	
Sullivan et al. (2007) <sup>96</sup>	100			35	
Lee et al. (2006) <sup>46</sup>	123			85	
Tinazzi et al. (2006) <sup>28</sup>	117			40	
Giuffrida et al. (2005) <sup>97</sup>	388			67	
Pain "directly related to PD"	Letro et al. (2009) <sup>54</sup>			50	54
	Goetz et al. (1986) <sup>50</sup>			95	46
Shoulder pain	Stamey et al. (2008) <sup>9</sup>			309	35
Burning mouth	Clifford et al. (1998) <sup>44</sup>			115	24

# Why does pain matter (2)?

- Associated with ↓QoL
  - The patient's perspective study (2010)
  - 265 PD patients
    - 92 early (<6 years)
    - 173 late (>6 years)

**TABLE 2.** Rank of the 24 most bothersome PD related symptoms/conditions in 92 early patients with up to 6 yr of disease duration

Rank	Symptom/condition	Total score	First choice %	Second choice %	Third choice %	3-Choice complaint prevalence (%)
1	Slowness	112	32.6	5.4	13.0	51.1
2	Tremor	101	29.3	8.7	4.3	42.4
3	Stiffness	76	6.5	26.1	10.9	43.5
4	Pain	50	9.8	9.8	5.4	25.0
5	Loss of smell/taste	30	3.3	9.8	3.3	16.3
6	Mood	28	4.3	6.5	4.3	15.2
7	Handwriting	18	2.2	3.3	6.5	12.0
8	Bowel problems	17	2.2	3.3	5.4	10.9
9	Sleep	15	2.2	4.3	1.1	7.6
10	Appetite/weight	13	0.0	3.3	7.6	10.9
11	Restless legs	11	1.1	1.1	6.5	8.7
12	Sexual dysfunction	10	2.2	1.1	2.2	5.4
13	Urinary problems	9	1.1	2.2	2.2	5.4
14	Fluctuating response to medication	8	1.1	2.2	1.1	4.3
15	Drooling	7	1.1	1.1	2.2	4.3
–	Sweating	7	0.0	1.1	5.4	6.5
17	Hallucinations/delusions	6	0.0	1.1	4.3	5.4
–	Memory	6	0.0	2.2	2.2	4.3
19	Compulsive behavior	5	1.1	1.1	0	2.1
20	Falls	4	0.0	1.1	2.2	3.2
–	Freezing	4	0.0	1.1	2.2	3.2
–	Speech	4	0.0	1.1	2.2	3.2
23	Fatigue	3	0.0	1.1	1.1	2.2
–	Swallowing	3	0.0	1.1	1.1	2.2
Other		5	0.0	1.1	3.3	4.3

**TABLE 3.** Rank of the 24 most bothersome PD related symptoms/conditions in 173 advanced patients with more than 6 yr of disease duration

Rank	Symptom/condition	Total score	First choice %	Second choice %	Third choice %	3-Choice complaint prevalence (%)
1	Fluctuating response to medication	115	15.0	8.1	5.2	28.3
2	Mood	96	7.5	12.1	8.7	28.3
3	Drooling	85	10.4	6.9	4.0	21.4
4	Sleep	83	9.8	5.2	8.1	23.1
5	Tremor	67	8.1	5.2	4.0	17.3
6	Pain	60	6.4	5.8	4.0	16.2
7	Bowel problems	46	4.0	4.0	6.4	14.5
8	Urinary problems	40	2.9	5.2	4.0	12.1
9	Falls	39	4.0	4.0	2.3	10.4
10	Appetite/weight	36	2.3	4.6	4.6	11.6
11	Slowness	34	3.5	3.5	2.3	9.2
12	Fatigue	31	2.3	2.9	5.2	10.4
13	Sexual dysfunction	29	4.6	1.2	0.6	6.4
14	Hallucinations/delusions	26	2.3	2.9	2.3	7.5
–	Restless legs	26	1.7	2.9	4.0	8.7
–	Speech	26	1.2	3.5	4.6	9.2
17	Compulsive behavior	25	3.5	1.2	1.7	6.4
18	Handwriting	23	2.3	1.7	2.9	6.9
–	Loss of smell/taste	23	1.7	1.7	4.6	8.1
–	Sweating	23	1.2	2.9	4.0	8.1
21	Stiffness	22	1.2	3.5	2.3	6.9
–	Swallowing	22	0.0	4.6	3.5	8.1
23	Freezing	21	2.3	1.7	1.7	5.8
–	Memory	21	1.2	1.7	5.2	8.1
Other		19	0.6	2.9	3.5	6.9

# Why does pain in PD matter?

- Because it's common
- Because it ↓ QoL

# Who gets pain in PD?

- Reported associations
  - Females
  - PD severity
  - Depression
  - Younger age
  - Motor fluctuations
  
- But.....

# PD pain classification

- PD associated and non-PD associated pain?
- Descriptors perhaps more helpful
  - Musculoskeletal
  - Dystonic
  - Neuropathic
  - Central
  - Akathisia
  - Others (e.g. oral and genital pain syndromes)

# Pain characteristics

- Musculoskeletal (80%) and dystonic (40%) most common
- Motor asymmetry reflected by pain
- Neuropathic pain usually not PD related
- Central pain
  - Poorly localised, constant, not obeying anatomy

# What generates pain?

- Immobility
- ?involvement of the BG in pain integration (with thalamus and cortex)
- ?abnormal central pain processing
- ?degeneration of nociceptors in periphery (damage to nerves in limbs)

# Do we ignore it (1)?

*Movement Disorders*  
Vol. 25, No. 6, 2010, pp. 704–709  
© 2010 Movement Disorder Society

The Nondeclaration of Nonmotor Symptoms of Parkinson's Disease to Health Care Professionals: An International Study Using the Nonmotor Symptoms Questionnaire

- 242 patients completed NMS questionnaire
- Average PD duration 8 years (1 to 28)

**TABLE 2.** *Number and percentage of positive and undeclared nonmotor symptoms*

Items		Positive		Non-declared	
		N	%	n	%*
1	Dribbling	101	41.7	46	45.5
2	Taste/smelling	103	42.9	41	39.8
3	Swallowing	65	27.0	24	36.9
4	Vomiting	38	15.8	16	42.1
5	Constipation	115	47.5	53	46.1
6	Bowel incontinence	15	6.3	5	33.3
7	Bowel emptying incomplete	65	27.0	31	47.7
8	Urgency	145	59.9	61	42.1
9	Nocturia	157	64.9	69	43.9
10	Pains	111	45.9	45	40.5
11	Weight	33	22.7	21	38.2
12	Remembering	124	51.2	55	44.4
13	Loss of interest	82	33.9	35	42.7
14	Hallucinations	41	17.0	17	41.5
15	Concentrating	121	50.0	46	38.0
16	Sad, blues	118	48.8	45	38.1
17	Anxiety	101	41.7	40	39.6
18	Sex_drive	90	37.3	41	45.6
19	Sex_difficulty	82	34.3	37	45.1
20	Dizzy	94	38.8	47	50.0
21	Falling	70	29.3	28	40.0
22	Daytime sleepiness	84	34.7	44	52.4
23	Insomnia	114	47.3	50	43.9
24	Intense, vivid dreams	84	34.7	44	52.4
25	Acting_out during dreams	93	38.7	41	44.1
26	Restless Legs	99	41.1	36	36.4
27	Swelling	91	37.6	33	36.3
28	Sweating	74	30.6	25	33.8
29	Diplopia	44	18.2	14	31.8
30	Delusions	23	9.5	15	65.2

\*Frequency and percentage calculated on the number of positive responses.

# Do we ignore it (2)?

- Pain
  - Not mentioned in AAN “Practice parameter: treatment of non-motor symptoms” 2010
  - Not mentioned in SIGN 113 (2010)
  - NICE 2006

# NICE 2006

- Pain is defined as an unpleasant or distressing sensory experience. Pain occurs in around 40% of people with PD but is rarely a major feature of the disorder
- Pain in PD has been classified as:
  - musculoskeletal
  - dystonic
  - primary or central
  - neuropathic
  - akathisia-related
- Little research has been done in this area and the management of many of these types of pain is generic rather than being specific to PD. Therefore, the GDG elected not to undertake a literature search in this area. The GDG did recognise the importance of dystonic pain which is often responsive to dopaminergic medications (see Chapter 7)

# Why do we ignore it?

- Patients
  - Perceive it's not part of PD?
  - Bad experience of discussing pain with medics before?
  - Nihilism about treatment?
  - Struggle to explain it?
  - Other reasons?
- Medics
  - Preoccupied with “proper” PD symptoms?
  - Just too hard?
  - Therapeutic nihilism?

# Summary

- Pain in PD
  - Common and contributes to misery of PD
  - Heterogeneous
  - Reasons poorly understood
  - Undeclared by patients and ignored by HCPs