

## Ways of Seeing: Doctors and Patients Talking about the Diagnosis of Parkinson's Disease — Ruth Pinder



Dr Ruth Pinder

Associate Research Fellow  
Centre for the Study of Health, Sickness and Disability  
Department of Human Sciences  
Brunel University  
UXBRIDGE UB8 3PH

### Curriculum vitae

Ruth grew up in the North of England and studied Social Sciences at Birmingham University. She worked in Australia, Israel and Ethiopia before returning to England as a Welfare Rights Officer in one of London's inner city areas. She studied for her MA in 1978 and gained her doctorate in 1984 from Brunel University, West London. She secured a research contract to study patient-doctor communication in Parkinson's Disease, and has since taught and written widely on the subject. She is currently Associate Research Fellow at the Centre for the Study of Health at Brunel University. Her husband was Director of Adult Education in the London Borough of Hounslow before retiring, owing to the onset of multiple sclerosis.

### Summary

*The way doctors and patients think about chronic illness is often hidden behind a mass of statistics. By using direct verbal reports, this paper explores the responses of GP and patient to the diagnosis of Parkinson's Disease (PD). Findings relating to their respective ideas about the drug treatment are discussed as well as PD as an age-related condition. It is suggested that sensitive communication requires doctors to address more fundamental questions of human suffering, and that counselling skills should be included as an integral part of the medical curriculum.*

*S Afr Fam Pract 1993; 14: 244-9*

### KEYWORDS:

Parkinson's Disease; Physician-patient Relations; Physicians, Family.

### Introduction

*"I suppose the diagnosis isn't a kind of crisis point usually. Patients obviously present with problems which means that now they have to do such-and-such, then they have to go home and think about it. But it's not like breaking a leg. Nothing very dramatic has to change. You don't have to think: 'Well, am I going to be able to get upstairs?' because presumably that problem may have arisen but it's not an acute problem"*

*"I was absolutely stunned, so much so that driving back I had to stop*

*because I was crying and couldn't see through the windscreen ... My husband was reading when I walked in. I went over to the bar as we always had plenty of liquor, but that's not like me. I hardly ever drink without someone offering me one. And I poured myself a brandy. He said 'What's the matter?' And then, of course, it all had to come pouring out. We didn't sleep all that night."*

This is a general practitioner (GP) and a patient talking about the diagnosis of Parkinson's Disease (PD). Yet it hardly seems as though the two are talking about the same phenomenon. My research question was: can we explain how, on the face of it, the two concerns seem to be so different? And, crucially, can we bring them closer together so that GPs may respond sensitively and effectively to their patients' distress?<sup>1 (a)</sup>

### Method

As the emphasis was on meanings and interpretations rather than on measurement and statistical analysis, a qualitative approach was used. This meant addressing 'how'? and 'why'? rather than 'how many'? and 'how much'? questions.

Initially I had intended to study specific pairs of patients and their own GPs. However, the first two patients I approached were reluctant to allow me to interview their own doctor. I can only speculate about their reticence: perhaps they feared that if interpretations were going to differ, their accounts might be given less credence.<sup>2</sup> As far as possible, my aim was to gain uninhibited responses.

This led to a major shift in the

## ... Ways of Seeing

PD did not fare too badly on this continuum. Above all, diagnosis did not threaten their own identities, their bodily or emotional integrity. We can call this indirect, experience-with knowledge.

For most patients in the study, diagnosis of PD was a critical turning-point in their lives. Nothing could ever be quite the same again,

---

Six years ago I thought I knew what PD was all about . . .

---

no matter how mild the presenting symptoms or how slow the progression of the disease. The orderliness and predictability upon which we normally base our lives was shattered.<sup>7</sup> An uneasy shadow now hung over patients' futures. This was direct, first-hand, experience-of knowledge.<sup>8</sup>

How may GPs bridge the gap? In seeking to reassure and comfort their patients, two considerations which reflected the values and beliefs GPs held about PD, and about patients with the condition, were uppermost in their minds.

#### *Something tangible on offer*

The availability of a treatment gave GPs a familiar handle with which to respond to patients. Diagnosis, followed by the instigation of therapy, accorded well with contemporary medicine's emphasis on the appropriate management of disease. Indeed, doctors considered that having something tangible on offer took some of the sting from a possibly distressing situation. It put off the day of reckoning. And GPs

did not immediately have to face in their patients much more painful areas of experience which many wanted to avoid. Dr S spoke feelingly of his relief:

*"It makes me feel much better! It makes you feel useful in the sense of being able to give something. It's much easier to hang a discussion around a change in medication, and that forever to be talking about how someone's continuing to get worse or to have episodes where they feel dreadful, where all you can say is 'That must be terrible', it does make you feel better to be able, perhaps, to give them something which might help."*

But, as GPs freely conceded, there were longer-term problems with the side-effects which could not be so neatly resolved. Nevertheless, for the

---

A big difference between knowing my partner may become disabled, and experiencing the reality of it in everyday life.

---

time being, they could draw up a reasonably coherent management plan. This was positive, goal-oriented medicine. Doctors could directly apply theoretical knowledge to solve concrete problems.

Most patients, too, were relieved to hear that PD could be treated and eagerly drew on what biomedicine had to offer. Initially it helped them regain some purchase on their lives. It restored their optimism, their faith in a world which had been so rudely disrupted. And patients had clear

expectations about treatment. As Mr I put it:

*"I just thought: 'Well, I've got an illness and the pills seem to be working and I'll just put up with it'. The treatment was so effective. It was a question of 'something needs to be done and I did it'. With the pills I could put the whole thing out of my mind."*

---

"You can alleviate suffering very often just by being there yourself."

---

Patients needed doctors' knowledge about the disease, and a treatment plan gave them a handle on it. Disillusionment only came later when, as Mr V discovered, "you notice things starting not to work": the treatment not only did not contain the condition; it had a life of its own as patients sought to disentangle the effects of the disease from the side-effects of the medication on their bodies.

#### *A question of age*

Most GPs in the study considered that age helped to soften the impact of diagnosis. As Dr W put it: "I think they more or less regard it as part of the ageing process". Other GPs felt that PD was much less distressing than illnesses which disabled patients before their lives had had a chance to flower. Dr C said:

*"I don't get that tragic feeling with Parkinson's that you obviously get with MS because with luck they'll be older, they will have had some quality of life. I'm not saying for*

## ... Ways of Seeing

*the individual person it's not tragic, but it's the overall concept. Younger people with Parkinson's Disease in their forties or fifties are disastrous, but that's a whole different order because you're dealing with much younger people".*

The orderliness and predictability upon which we normally base our lives, was shattered.

Doctors thought this was a reasonable approach. It accorded with both lay and medical beliefs in a culture where youth is generally highly valued, aesthetically and economically, and old age stigmatised.

However, the picture was not so straightforward for patients. In trying to make sense of their plight, the fact that they were older did not necessarily ease their feelings. Age itself was not always accepted with equanimity. To be diagnosed as suffering from an incurable, degenerative disease merely intensified the pain. Mr R thought:

*"When Parkinson's came along, it was a blow. I had the feeling here was something else to make you feel old. What did someone say? Every day after retirement they regard as a bonus. Every day after Parkinson's I don't regard as a bonus. Is this what you're given to finish your time off with?"*

Age and chronic illness were experienced as a double burden.<sup>9</sup>

Other patients felt cheated just as they were approaching a time in life when financial and family pressures had eased and they were free to enjoy themselves. No age was a good age to have PD.

Experience of knowledge was very different from the detachment offered by those whose identities were not personally threatened.

## The missing link

The questions that most bothered patients were of a different order, going beyond strictly biomedical ideas of causation and scientific rationality. Patients faced the task of finding explanations for the nature of human suffering, an issue on which, as Stacey<sup>10</sup> points out in her review, clinical medicine is largely silent. The

Long-term problems with side-effects could not be so neatly and easily resolved.

wife of Mr C, who had recently been diagnosed, illustrates the pain of such a quest:

*"So much in life hasn't gone right in these last few years that my faith in God has been very sorely tested ... My husband's been such a good living, decent man, it doesn't seem fair. You look at some people you can only describe as worthless rotters, and nothing seems to happen to them. Life swims by for them. Why has it happened to him?"*

For patients, trying to explain why

they, rather than 'someone else' had been struck down with a chronic illness was part of the need to make sense of life's many other catastrophes.<sup>11</sup> GPs trod warily on the issue. Doctors in the research

Patients needed the doctor's knowledge about their disease, and a treatment plan gave them a handle on it.

generally were reluctant to become involved, feeling that the structure of general practice in Britain made it impossible to devote the time required. However, Dr Y ventured:

*"You can alleviate suffering very often just by being there yourself, and I think it's important to recognise that as an important thing to do. I know it sounds trite. I'm getting a bit better at it. I don't know whether it comes to you as you get older?"*

Attending to patients' "language of distress"<sup>12</sup> was important, but doctors found there were few rules to guide them. Yet, for patients, the urge to impose order on disorder, was central to their experience of illness. Whilst doctors' theoretical and practical knowledge provided a framework around which patients could work, this, on its own, did not suffice.

## Conclusions: match and mismatch

As exponents of contemporary Western medicine, how far are GPs in tune with the needs of patients with PD and other chronic illnesses? We can see that the different ways

## ... Ways of Seeing

doctors and patients think about PD are likely to have important effects on the patient-doctor relationship. In this study, GPs' experience-with knowledge could readily lock into patients' beliefs about treatment directly after diagnosis. But whether age tempered the impact of the bad news was much more equivocal.

---

There is a person to be understood behind every patient.

---

Further, treatment itself was only a partial and short-term answer. Later, GPs would have to confront both their own feelings of helplessness and inadequacy, and their patients' distress when strictly medical solutions ran out. Clinical science has few categories with which to address more fundamental questions of human suffering.<sup>13</sup>

Experience-with and experience-of knowledge are often seen as representing opposite sides of the coin. One is considered to be superior, objective, rational and reliable; the other inferior, subjective, woolly, and unreliable.<sup>14</sup> Ideally I see them as complementary, with doctor and patient working as partners, making a journey of discovery together.<sup>15</sup>

This involves sharing each others' knowledge and experience, with mutual respect for what each can contribute. Doctors need *patients'* knowledge to gauge whether they are communicating effectively or not.

For a genuine partnership to take place, it is important for GPs to move

beyond the confines of strictly biomedical beliefs, to try and grasp something of what it is like to have PD first-hand. Three steps are necessary.

First, GPs could scrutinise the judgements they use. This is not to say that there is no need for judgements. Rather, beliefs need to be adapted, modified and often re-defined to remain in step with the way patients think and feel. There is a person to be understood behind every patient.

Secondly, and much more difficult, is the task of stepping into another's shoes. We cannot transcend the limitations of our own experience except perhaps fleetingly.<sup>16</sup> My research<sup>17</sup> showed that GPs who could reach into their patients' worlds, even if only for a few moments, transformed patients' ability to come to terms with the condition. This raises a vitally

---

Patient: "I noticed things starting not to work..."

---

important dilemma for GPs. It asks them to confront the inner pain of others, raising the very anxieties which may most disturb themselves.

Thirdly, a broader appreciation of the social and cultural contexts in which patients experience chronic illness is necessary. Experience-with knowledge occupies a privileged position in contemporary Western society,<sup>18</sup> but it fails to explain why some people fall prey to sickness whilst others escape apparently unscathed. To communicate

effectively, GPs need to freely draw on both personal and cultural frameworks of making sense of what has happened, and thus to squarely address questions of misfortune and human suffering. To do so raises as many problems as it is likely to resolve. But can doctors afford not to

---

Age plus chronic illness were experienced as a double burden.

---

do so? The inclusion of core counselling skills as an integral part of the medical curriculum, rather than as a soft option to be tacked on at the end as a concession to liberalism, might be a way forward.<sup>19</sup>

At the end of the day, I believe most GPs would wish their patients to feel like Mrs U who said of her own GP:

*"I suppose there is a bond really. I feel he understands perfectly how I feel. I know when I go in he's going to understand".*

## References

1. Pinder R. The Management of Chronic Illness: Patient and Doctor Perspectives on Parkinson's Disease. Basingstoke: The Macmillan Press; 1990.
2. Becker H S. Whose side are we on? Soc Problems 1967; 14: 239-47.
3. Hunt J. Psychoanalytic Aspects of Fieldwork, Qualitative Research Methods. 18, 1989; Newbury Park: Sage.
4. Hugo J F M. Experiences of sickness and healing by poor rural families in Lebowa. S Afr Fam Pract 1992; 258-64.
5. Kleinman A. The Illness Narratives: Suffering, Healing and the Human Condition. New York: Basic Books, 1988.

## ... Ways of Seeing

6. Russell, B. *The Problems of Philosophy*. London: Oxford Univ. Press 1967.
7. Murphy R F. *The Body Silent*. London: J M Dent 1987.
8. Pinder R. Coherence and incoherence: doctors' and patients' perspectives on the diagnosis of Parkinson's Disease. *Soc Hlth Illness*, 1992; 14, (1), 1-22.
9. Trieschmann R B. *Aging with a Disability*. New York: Demos Publishers, 1987.
10. Stacey M. *The Sociology of Health and Healing: A Textbook*. London: Routledge, 1991.
11. Kleinman A, Eisenberg L, Good B. *Culture, Illness and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research*. *Ann Intern Med* 1978; 88: 225-58.
12. Young A. The relevance of traditional medical cultures to modern primary health care. *Soc Sci Med* 1983; 17: 1205-11.
13. Helman C. *Culture, Health and Illness*. Bristol: John Wright, 1985.
14. Cobb A K, Hamera E. Illness Experience in a Chronic Disease - ALS. *Soc Sci Med* 1986; 23: (7): 641-50.
15. Tuckett D, Boulton M, Olson C, Williams A. *Meetings between Experts: An Approach to Sharing Ideas in Medical Consultations*. London: Tavistock, 1985.
16. Wilmer H A. The Doctor-patient Relationship and the Issues of Pity, Sympathy and Empathy. In: Stoeckle J. (Ed) *Encounters between Patients and Doctors: An Anthology*. Camb Mass: M I T Press, 1987.
17. Pinder R. (1990), op.cit.
18. Stacey M. op.cit.
19. Silbert M V. Basic Communication and Counselling Skills in the Training of Doctors. *S Afr Fam Pract* 1987; 8: 183-5.

## Acknowledgements

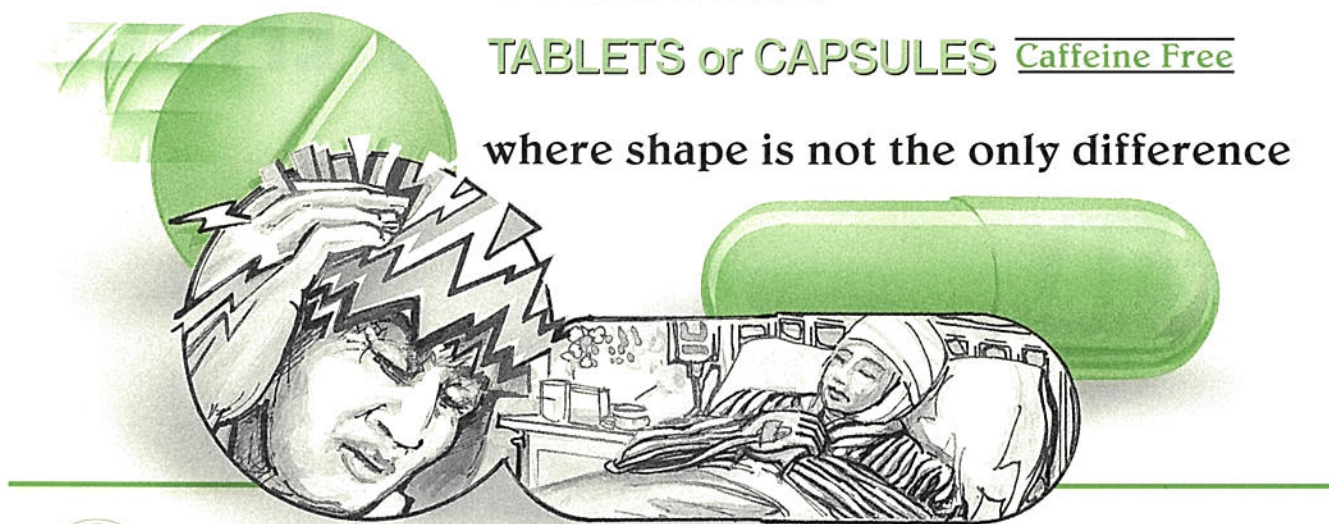
*I gratefully acknowledge the support of the Parkinson's Disease Society in funding the research for this paper.*

## To relieve pain and tension

# STILPANE<sup>®</sup>

## TABLETS or CAPSULES Caffeine Free

where shape is not the only difference



Uncompromising Commitment

280 Kent Avenue Ferndale Randburg 2194 P.O. Box 2251 Randburg 2125 TEL: (011) 886-4060 FAX: (011) 789-4541

SS STILPANE Tablets. Contains Paracetamol 320mg, Codeine Phosphate 8mg, Caffeine Anhydrous 32mg, Meprobamate 150mg, preservative Nipastat 0,02% m/m  
Reg. No. M/2.9/2 SS STILPANE Capsules. Paracetamol 370mg, Codeine Phosphate 8mg, Meprobamate 185mg. Reg. No. B624 Act 101/1965