

The lived experience of Parkinson's
'A footprint in every room'

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Abstract

Background: This PhD is part of the Wellcome Trust funded London and Brighton Translational Ethics Centre (LABTEC) Project investigating the social impact of developments in stem cell research and neuroscience. It contributes to the overall project by giving voice to the patient experience when faced with Parkinson's, a serious progressive, degenerative and incurable neurological disease.

Aim: The aim of this study is to provide a rich narrative account of how individuals diagnosed with Parkinson's negotiate their illness, paying particular attention to the personal, social and historical conditions that mediate people's stories.

Methods: The study uses the data emerging from 37 interviews conducted with individuals whose experience of a Parkinson's diagnosis ranged from 3 months to 33 years, and whose age at diagnosis ranged from 29 to 78 years. Methodologically, it is informed by Arthur Frank's concept of dialogical narrative analysis (DNA), at the heart of which lies the desire to hear the different voices in any one person's story. DNA is interested in hearing how stories shape participants' understanding and experience of illness. At the same time, it recognises that stories have no ending because people constantly retell them in order to develop and revise their understanding of self.

Findings: This study illustrates the importance of stories in enabling participants to reclaim their experience of Parkinson's from others' narrative representations of them. It also gives voice to the human significance of diagnosis after finding that, for many participants, the diagnostic encounter not only lacked ceremony but was also a point at which their voices were all but silenced. Finally, using Frank's illness typology of restitution, chaos and quest as a 'listening device,' it becomes possible to hear the existential challenges facing participants as they try and make sense of their illness in the context of a society where restitution remains the preferred narrative and the search for a cure remains a stated goal of scientific research into Parkinson's disease.

Conclusion: The final thesis is a methodologically novel contribution to empirical bioethics which will inform discussions around policy and practice relating to the care and treatment of people with this particular neurodegenerative disease.

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Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to these or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed

Dated

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CHAPTER 1: INTRODUCTION

This thesis is about stories. Most importantly it is about the story of Parkinson's disease, a progressive, degenerative, incurable neurological disease that has the power to affect all aspects of a person's life as well as that of their family. However, it is also about my role as a researcher, hearing these stories and presenting them in what has become a quest narrative in its own right.

1.1 Organisation of this thesis

The thesis comprises seven chapters.

Chapter 1 briefly introduces this study and outlines the organisation of the thesis.

Chapter 2 begins by discussing how Parkinson's is described in the medical literature, including recent moves to redefine Parkinson's disease as a neurocognitive-psychiatric disorder. It briefly touches upon issues relating to the diagnosis, aetiology, prevalence and treatment of Parkinson's before outlining current medical and scientific research interests. The chapter continues with a critical appraisal of the qualitative literature, not only to situate this study historically, but also to establish any ongoing debates and gaps within contemporary research. It concludes with reflections on how the literature is incorporated and used within this study.

Chapter 3 provides an in depth examination of the methodological approach adopted in this thesis. The chapter explores the researcher journey, including the inception and design of the study, the methods used to implement the design, and the decision to adopt an approach using dialogical narrative analysis (DNA). It then discusses the implications of using a DNA approach and the challenges inherent in presenting participants' illness stories. The chapter concludes by explaining the differing approaches adopted for the analysis and presentation of data over the following three chapters.

Chapter 4 is the first data chapter. It experiments with the concept of dialogical narrative analysis by placing participants' voices into dialogue with 'official' accounts of Parkinson's. It shows how individuals start to talk about their illness in response to an external disease narrative that is shaped by 'culturally shared stories.'

By allowing participants to respond to narrative representations of their disease, it also offers considerable insight into the personal, social and historical conditions that mediate people's stories.

Chapter 5 is the second data chapter and presents participants' accounts of the diagnostic encounter. Its particular interest lies in the moment of diagnosis and 'reassembling' diagnosis conversations, which are occasionally discussed but rarely heard in the literature. The chapter places the 'human significance' of diagnosis centre stage.

Chapter 6 is the third and final data chapter and builds on the stories that emerged in the previous two data chapters. Using Arthur Frank's typology of illness as a 'listening device' to explore how people narrate their stories of illness, it presents three different narrative accounts of Parkinson's disease, each considered as a whole. Each of these personal illness narratives builds on the 'human significance' of diagnosis (chapter 5) within the context of the disease story (chapter 4). They do not claim to be representative of the experience of Parkinson's, but they do provide three vivid accounts of 'the generalised problem' of talking about the lived experience of a progressive, degenerative, incurable condition.

Chapter 7 is the final chapter. It explores this study's contribution to the literature on Parkinson's; reflects on some of the challenges experienced while undertaking this study; and briefly discusses implications for future research.

1.2 Endnotes and footnotes

I have made use of endnotes (and occasional footnotes) throughout this thesis, with the exception of the final chapter. Whilst I have used endnotes only sparingly in chapters 2, 3, 5 and 6, I have made extensive use of them in chapter 4. This possibly reflects my original training as a historian and my desire not only to offer a thorough overview of the historical development of the Parkinson's narrative but also to offer additional context to some of the sources from which I have drawn ideas. Whilst the endnotes are not essential to an understanding of the text, I have included them out of respect for the sources as well as to give additional information and references.

1.3 Appendices

I have included a number of appendices in this thesis. Whilst they include official letters (ethics approval) and information directly relevant to recruitment (participant information sheet etc.), I have also included a number of appendices that expand on information or arguments within the main text. The reason for doing so is a direct consequence of my methodological approach, which required that I use comparatively few stories from the original collection of thirty-seven. My use of appendices has therefore been a means of offering additional insights from participants whose voices otherwise remain in the background.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Parkinson's disease is an incurable, degenerative, progressive condition. Although traditionally viewed as a neurodegenerative movement disorder and still diagnosed on the basis of 'characteristic motor features' (bradykinesia, resting tremor, rigidity or postural instability), it is a 'complex neurological disorder with devastating neurobehavioural symptoms and psychosocial consequences' (Calne 2003, p.312) that strongly affects all aspects of everyday life. Considerable momentum has built up over the last few years in an attempt to redefine Parkinson's disease as a neurocognitive-psychiatric disorder (Weintraub and Burn 2011, Chaudhuri 2013, Todorova, Jenner et al. 2014). In addition, studies aimed at measuring the Health related Quality of Life (HRQoL) of people with Parkinson's have, in the last decade, shifted their emphasis from the effects of rigidity, bradykinesia, tremor, gait and balance problems, to the role of non-motor symptoms such as sleep, mood, cognition, pain and autonomic disorders (Martinez-Martin, Rodriguez-Blazquez et al. 2011, p.400). There is increasing evidence that 'non-motor dysfunction' precedes - possibly by decades - clinical manifestations of the motor symptoms (Poewe 2008, Chaudhuri 2013). Since 2006, the Non-Motor Symptoms Questionnaire and Non-Motor Symptoms Scale have been introduced, the former in an attempt to 'flag up' symptoms that may otherwise not be declared, and the latter to 'monitor the effect' of interventions related to non-motor symptoms (2011, *ibid.*). However, despite research showing that the burden of non-motor symptoms contributes negatively to a patient's health-related quality of life, there is still concern that many clinicians regard these symptoms and their management as 'peripheral' to that of the motor symptoms (Todorova, Jenner et al. 2014, p.310).

The number of scientific papers produced in recent decades indicates extensive research activity into Parkinson's¹ and the ultimate stated goal of scientific research is to find a cure for Parkinson's. This goal is reflected in the straplines of some of the major charities involved in research (see Figures 1 and 2 below).



Figure 1 Poster used by the Parkinson's Disease Foundation

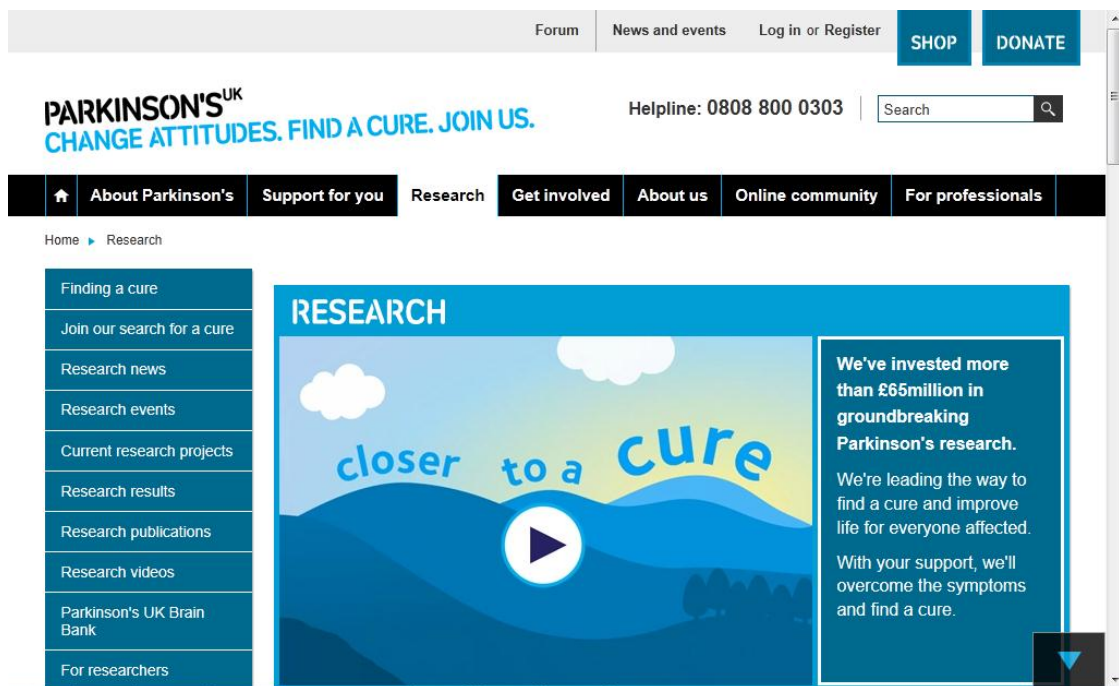


Figure 2 Parkinson's UK Research page - February 2015²

Nevertheless, the aetiology of the disease remains uncertain; there are, as yet, no reliable bio-markers; and diagnosis can still only be made with certainty at post-mortem^a (Chaudhuri, Clough et al. 2011, p.9). The heterogeneity of disease progression can be 'enormous' and progression of motor impairment might differ significantly in people with similar disease duration (Maetzler, Liepelt et al. 2009). Current research is therefore wide-ranging and includes gaining a better understanding of the genetic, as well as environmental, causes of Parkinson's; searching for biomarkers that may help detect Parkinson's before the motor symptoms manifest themselves; and developing more effective treatments. At present, treatments are available which help reduce the severity of Parkinsonian symptoms initially, but many result in serious side effects. Another aim of research,

^a Accurate diagnosis depends on the presence of Lewy bodies in the substantia nigra or other regions of the brain. This can only be established after death.

therefore, is to develop treatments that will not only control the symptoms of Parkinson's, but also slow down, halt or even reverse the rate at which it progresses.

In addition to drug treatments, deep brain stimulation is considered effective for individuals with advanced Parkinson's who no longer benefit sufficiently from L-dopa and do not suffer from severe neuropsychiatric symptoms or dementia (Haahr, Kirkevold et al. 2010, p. 1229). Although validated as an effective therapy for reducing dyskinesias and motor fluctuations, uncertainty still hangs over the optimal timing of surgery and also the long term outcome (i.e. more than five years after surgery) of the procedure (Fahn 2009). Other surgical approaches to therapy, including gene therapy, are now in clinical trials, and there has been a recent resurgence in hope around the use of stem cells.

Whereas scientific research papers abound, the same may not be said about research aimed at understanding the lived experience of Parkinson's. Unquestionably the 1990s and beyond have seen a 'rapid proliferation' of qualitative research examining the lived experience of chronic illnesses in general, and yet 'the frequency with which *certain chronic diseases* [have attracted] qualitative research attention is in no way proportional to their population distribution' (Thorne 2002, p.444). Diseases identified as under-represented in the literature at the time of Thorne et al's study included 'stroke, amyotrophic lateral sclerosis,^b Huntington's chorea, and Parkinson's disease' (ibid.) and the authors observed that they were all conditions that influence and negatively affect verbal communication. Although this meta study was published over ten years ago, it is still the case that the number of truly qualitative studies published about Parkinson's in the intervening years remains small. This suggests that, despite being one of the 'most common neurodegenerative diseases' (Chaudhuri, Clough et al. 2011, p.9) it is nevertheless a condition that remains 'disproportionately unpopular' as a research topic (Thorne 2002, p.444).

^b ALS is usually called motor neurone disease (MND) in the UK.

2.2 Purpose and scope of the literature review

The chief purpose of my literature review is to situate this study historically, as well as establish ongoing debates and gaps within the qualitative literature related to Parkinson's. How far back a literature review should date may be considered contentious, but given that the field of qualitative research about Parkinson's is relatively small, it feels appropriate to present an overview and evaluation of the literature from its inception to the current time, at the same time recognising that no review can ever be exhaustive. Although I have made reference to the information available via the internet, this chapter does not include a formal review of material published on line. Nor does it include a formal review of all [self-] published autobiographical accounts.

The way in which I write this review may feel unconventional at times. This is in order to reflect a methodological approach that makes more sense if it imbues the thesis as a whole rather than only the chapters focusing on my participants' stories. The latter, as already stated in the introduction, are central to this thesis. But participants' stories do not exist in a vacuum. Rather, they have come into existence in their current form as a consequence of this study - itself the result of a complex web of interactions, all of which have their own stories to tell.

The literature review, as a key part of this complex web, has involved considerable detective work. At times it has felt akin to piecing together an enormous jigsaw puzzle for which only the title – not the picture – remains. The process has been far from linear, interspersed with frequent false leads (often fascinating) as well as unexpected connections. Following these leads and connections has been vital for gaining an understanding of the extant literature, which has, in turn, helped guide me towards my methodology.

To illustrate the process at work, I have written the following section (2.3) in the form of a story which, in its simplest form can be understood as how 'one thing happens in consequence of another' (Frank 2010, p.25). At the same time, it helps illustrate the truth inherent in Bruner's observation that 'we're constantly scanning the world selectively [...] to find the kind of thing we're looking for' (2002, p.4).

2.3 The seeds of this literature review

This literature review finds its starting point in a small book recommended to me by one of my fellow LABTEC PhD researchers. Anna had started her PhD^c a few months before me and, at our first meeting, helpfully told me about a quirky book she had read called ‘Ponderings on Parkinson’s – An Inside View of Parkinson’s Disease’ (Nock 2007). I seized upon her recommendation, ordered a copy and, the moment it arrived, allowed myself the luxury of sitting down and reading it from cover to cover.

In her introduction, Sarah Nock explains that the seed for her book was sown by a ‘gratuitous letter’ she wrote to her neurologist, in which she lamented that:

Whenever I read something about Parkinson’s, or hear a radio programme or watch a television one, I never feel any the wiser. I mean, I might feel more clued up about what is being done for us and other lovely things, but if I didn’t have it myself I would be no nearer knowing how it actually felt. And I found no one seems to have any idea – until I tell them (2007, p.13).

She continues with the reflection that, having written the letter to her neurologist, she felt:

...glad to get that off my chest; it was frustrating that no one seemed to have any idea of what Parkinson’s felt like, not even the doctors in the large teaching hospital where I volunteered for a couple of brain scans and having electric shocks to my head – no, certainly not them.

She then forgot about her letter until:

...to my surprise, I had a lovely letter back. Professor Lees³ said he found my letter helpful, that he himself found it difficult to comprehend the nature of the condition as experienced by his patients; he needed to hear it from the horse’s mouth (ibid. p.14).

Subsequently, in the foreword to her monograph, Professor Lees emphasised the importance of narrative in the daily practice of doctors, pointing to the fact that ‘the

^c Her PhD explored ‘Patient representation and the research agenda in neurodegenerative disease’ (Anna Grinbergs-Saull, 2014).

art of medicine, with its goals of accurate diagnosis and appropriate treatment, depends on listening to patients' tales.' Furthermore, rather than denigrate the role of narrative within medicine as 'an outmoded anti-scientific tradition,' he stressed the need for doctors to 'listen and empathise.' Above all, he suggested that with biomedicine moving 'closer to becoming a pure science in its laboratories,' it was vital that 'at the bedside it remains a patient centred interpretative practice' (ibid. p.9).

Given the nature of my research, with its focus on giving voice to people with Parkinson's, it was of interest to read that a well-respected neurologist, with many years' experience working in the field of Parkinson's, acknowledged difficulty in comprehending the lived experience of this degenerative condition. It was also heartening to read his endorsement of the role of narrative within medicine at such an early stage of my research design.

A few months after reading 'Ponderings on Parkinson's' I watched the film 'Awakenings,' which in turn prompted me to buy the book.⁴ Written c. 35 years before Professor Lees' foreword, the resonance between their views is evident as Sacks argues for empathic and biographic thinking, believing it 'insufficient to consider disease in purely mechanical or chemical terms' when trying fully to understand a patient's experience of their illness (Sacks 1973, p.xviii). A little over ten years later, in increasingly strident voice, he criticises the modern case history, with its tendency to reduce a person to a 'cursory phrase,'⁵ and argues that in order 'to restore the human subject at the centre - the suffering, afflicted, fighting, human subject - we must deepen a case history to a narrative or tale: only then do we have a 'who' as well as a 'what,' a real person, a patient, in relation to disease - in relation to the physical' (Sacks 1985, p.xii).

2.4 Patient voices

It is just this problem of reductionism that Ruth Pinder sought to tackle in her 10 month longitudinal study "Striking Balances: Living with Parkinson's disease"(Pinder 1988). Indeed, she gave her research article the subtitle "The Patient's Perspective: A Neglected Topic?" and explained that its aim was to 'penetrate the life experience of those who have Parkinson's disease (PD)' (ibid. p.67). Pinder, who at that point was a social science researcher at the University of

Brunel, noted that, since the publication of Parkinson's "Essay on the Shaking Palsy" in 1817, any accounts of Parkinson's had been written mainly by doctors and scientists, plus a handful by epidemiologists and paramedics. She observed that accounts remained 'normative and prescriptive,' with the 'honourable exception' of Oliver Sacks' contribution (ibid. p.67). She also noted that, apart from a two page account of living with Parkinson's by the psychiatrist Cecil Todes⁶ (Todes 1983), autobiographical contributions to the literature up until that point were almost exclusively from the United States, such as the 1981 account of 'Parkinson's – A Patient's View' by Sidney Dorros – an account that was not published in Britain until 1998.

In the interest of historical accuracy, it is worth noting two autobiographical accounts to which Pinder made no reference. The first is Margaret Bourke White's 1963 Memoir (again from the U.S.A.) that included two remarkable chapters describing the effects of Parkinson's and her decision to undergo pioneering surgery at a time when drugs were not yet available to help relieve the symptoms (Bourke-White 1963).⁷ The second is a British contribution: Ivan Vaughan's autobiography, "Ivan: Living with Parkinson's disease," published in 1986, two years after he had taken part in a BBC Horizon documentary, the eponymously named 'Ivan', in which his search for a cure was explored.⁸

Finally, although she mentioned James Parkinson's contribution, Pinder omitted to mention fascinating insights into the condition made by the Prussian scholar and reformer, Wilhelm von Humboldt (1767-1835), whose observations about himself give, according to contemporary Parkinson's experts, an 'even more comprehensive description' of Parkinsonian symptoms than does James Parkinson's 'astute essay' (Horowski, Horowski et al. 2000, p.205).

In an analysis of von Humboldt's writings, Horowski et al have matched his self-descriptions to some of the key manifestations of Parkinson's, including a resting tremor, bradykinesia, rigidity, micrographia (abnormally small handwriting), a masked face (hypomimia), slow movements and gait, and postural changes. Whilst von Humboldt apparently viewed these symptoms as 'nothing but common ailments associated with ageing - which, in his own case, he feels, did occur quite early and suddenly in the aftermath of the death of his wife Karoline' (ibid. p.206), such

reflections are fascinating - not least because they illustrate so beautifully a theory that was to be proposed over 150 years later by the American sociologist, Eleanor Singer – that of ‘premature social ageing.’



Figure 3 Statue of Wilhelm von Humboldt by Friedrich Drake (1834)

Through comparing the social and economic functioning of a sample of people with Parkinson’s with that of a sample of people of similar age within the general population, she observed that ‘the activity levels of Parkinson patients at a given age correspond to those of people chronologically older’ and ultimately concluded that ‘the social consequences of Parkinsonism, and probably of many other chronic illnesses, can be likened to a premature social ageing of the individuals affected.’ She also noted that it impinged much more heavily on those who acquired Parkinson’s earlier than is the norm (Singer 1974, p.143).

Although published over a quarter of a century ago, Ruth Pinder’s study is still of significance not only because it was one of the first designed to listen to the views of people with Parkinson’s and focus on ‘subjects’ definitions of the problem rather than those of the researcher’ (1988 p.70), but also because – as will be discussed - some of her ideas still resonate strongly in current debates. It is also of importance given that it was conducted in the early days of the availability of a therapeutic treatment – Levodopa. As she presciently wrote:

The use of Levodopa increases the life span of those with PD, but this increased longevity brings further social, medical and biographical complications in its wake. Levodopa is a young drug, in use only since 1969, and its implications for end-of-career quality of life have yet to be fully understood' (ibid. p.85).

Whilst stating that her aim was *not* to establish generalisations from her findings, she nevertheless concluded that living with Parkinson's required sufferers to develop expertise – both in coping with it on a daily basis as well as handling a fluctuating drug regime – and thus suggested the need for a 'participatory model' of information sharing and decision making.

It is important to remember that Pinder was writing at a time when 'few subjects had been socialised into expecting to share with their doctors in any decision-making process' (p. 84), as a consequence of which 'the dependence of doctors on patients' own evaluations of what is going on in their bodies [was] perhaps one of the more equivocal considerations involved in managing the drug regime' (ibid.). It is also clear that whilst some of Pinder's participants reacted adversely to being 'given permission' to adjust their own dosage, the views of the medical profession towards participatory decision making were similarly not clear cut. Indeed, the ambivalence at that time is illustrated by the experience of the aforementioned Ivan Vaughan, whose decision to experiment with his own treatment was not received favourably by the medical profession. In the foreword to Vaughan's book, Jonathan Miller – who had spent considerable time with him in the filming of a BBC documentary⁹ for Horizon about his experience of Parkinson's – wrote:

Because he is an unusually curious patient who regards his condition as something to be explored as well as endured, Ivan juggles with his own treatment and, in the knowledge that he can always run to the drug for shelter, he sometimes takes pharmacological holidays so that he can experiment with the transition from one to state to another. As far as the medical profession is concerned, this sort of therapeutic improvisation is short sighted and irresponsible and any adjustments are best left to those who are in the know.

He continues with his observation that:

Although doctors pay lip-service to the principle that all patients should be listened to, the intelligent sufferer often comes away from the clinic with the distinct impression that he or she has been seen without actually being heard. And since many of the vicissitudes of the disease cannot be observed and have to be described, the patient's spoken testimony is one of the most valuable sources of information (Vaughan 1986, p.xiv).

Miller argued that, although Vaughan was seen to have rocked the boat unhelpfully, nevertheless a situation existed whereby:

As medicine becomes more scientific, its official literature leaves less and less room for the subjective accounts provided by patient, and as the discourse becomes denser and more impenetrable, it becomes harder and harder to hear the voices of those for whom the benefits are designed (ibid. p xv.).

2.5 How past links to present: A contemporary view

There has been considerable societal and cultural change since Pinder's study and Vaughan's account. The advent of the internet and inception of the World Wide Web has led to a plethora of medical information becoming readily accessible to the layperson at the touch of a button.^d Someone diagnosed with Parkinson's may now find information about their condition from many internet-based sources, including medical websites, Parkinson's charity websites or open access publications. Should they so wish, individuals affected by Parkinson's may discuss their concerns in internet 'chat rooms' or read others' accounts of living with Parkinson's in personal blogs. It is also worth noting that the World Wide Web, free for anyone to use since 1993, has enabled self-publishing to flourish, and there are now considerably more 'autobiographical contributions' than at the time of Pinder's study.¹⁰

As already mentioned, the scope of this literature review precludes an in depth evaluation of self-published autobiographical accounts or the many web-based resources relating to Parkinson's although, where appropriate, I shall draw on and

^d Putting 'Parkinson's disease' into a search engine on one day in March 2015 yielded 14,800,000 results.

reference websites and web-based information during the course of this thesis.

Before moving on to a review of the body of qualitative research that has emerged in the wake of Pinder's study, I wish to draw attention to two of the issues that she highlighted which, despite societal change, still resonate in contemporary debates pertaining to Parkinson's: the issue of the 'patient's perspective' and the issue of the need for a 'participatory model of information sharing and decision making' within the healthcare system. Both issues retain currency and have, for example, been emphasised through the highly respected web-based platform – healthtalkonline.¹¹ In an apparent reference to the importance of maintaining links with what has gone before, the healthtalkonline website uses a brief video clip of Jonathan Miller to introduce the Parkinson's disease section of their website. The latter provides a powerful platform for disseminating information through film, thereby enabling website visitors the opportunity of not only hearing personal stories, but also seeing the narrators.

From my perspective as a researcher into the lived experience of Parkinson's, it is of particular interest that the desire to be heard and understood continues to be reflected not only in the words of people affected by Parkinson's (such as Sarah Nock, above) and the medical profession (Professor Lees, above) but also by contemporary health researchers who, in the case of the healthtalkonline project, have felt moved to write that "People with Parkinson's are sometimes desperate for others to understand what it is like to be them."

As mentioned in the introduction, the number of UK based qualitative studies examining the experience of Parkinson's from the perspective of the patient remains small. However, read alongside studies emerging from other countries, they provide valuable insight into a chronic, progressive, degenerative illness that affects 'the entire lifeworld' of the person living with Parkinson's (Haahr, Kirkevold et al. 2011). Given the complexity of Parkinson's, not least its myriad symptoms and the difficulties inherent in alleviating them, it is perhaps not surprising that many of the studies have been conducted by researchers with a background in nursing or medicine, usually with clear aims about informing practice, either within the health or voluntary sectors, and often garnering particular perspectives – i.e. targeting particular 'patient groups' (e.g. by gender and/or age or 'stage' of disease) or particular 'symptoms' (e.g. difficulty swallowing or, 'freezing' or sleep

disturbance). This disciplinary orientation has been criticised, with the suggestion that some of the research, rather than establishing ‘who has a story to tell’ is, instead, ‘pre-defined by professional health care workers,’ thereby remaining ‘deeply rooted in clinical application’ (Nijhof 1996, Thorne 2002). Whilst this may be the case, a diversity of approaches seems appropriate for the exploration of a disease as complex as Parkinson’s, and the importance of the small body of qualitative literature that has built up around Parkinson’s lies in the commitment of researchers to listen to, and hear, the views of the person affected by Parkinson’s.

Indeed, shortly before writing this review, my attention was drawn to a paper authored by highly respected researchers and practitioners in the field of neurology, entitled ‘Non-motor Parkinson’s: integral to motor Parkinson’s, yet often neglected’ (Todorova, Jenner et al. 2014). The stated aim of the paper is to address ‘the clinical issues and unmet needs of non-motor symptoms in Parkinson’s disease.’ The authors explain that non-motor symptoms ‘can define a patient’s health-related quality of life’ and yet there remains the concern that ‘clinicians often regard non-motor symptoms and their management as peripheral to that of motor symptoms’ as a consequence of which they ‘overlook’ them, do not discuss them, or simply ‘may not realise that [they] need addressing’ (ibid. p.310). This contemporary view of the clinical encounter from the perspective of neurologists provided me with a new lens through which to re-appraise the qualitative literature and reinforced my decision to include ‘older’ literature, the findings of which, despite dating back a quarter of a century, still have resonance.

2.6 Multi-dimensional nature of Parkinson’s

With this in mind, it is striking that over twenty years ago, qualitative studies aimed at a general understanding of Parkinson’s disease from the perspective of the diagnosed individual, whilst limited in number, made clear that the burden of Parkinson’s lay well beyond the ‘motoric domain’ (Dakof and Mendelsohn 1989, Marr 1991, Brod, Mendelsohn et al. 1998). Although these studies found that motor difficulties, including loss of mobility and a decline in physical capacity, were of significant concern to participants, they established that the illness experience was ‘multidimensional’ in nature, encompassing ‘cognitive, interpersonal, psychological [as well as] motoric domains of functioning’ (1998, p.213 & p.221, U.S.A.).

Fatigue and a general depletion in energy levels, compounded with motor difficulties, were found to affect not only daily activities within the home, but also occupational and recreational activities. In addition, communication difficulties, anxiety, depression, loss of independence and increasing social isolation were reported as being of major concern to participants. Thus, people's perception of their well-being and general health are more strongly influenced by their mental health symptoms (particularly depression and anxiety) than their physical symptoms (Chrischilles, Rubenstein et al. 2002). This multi-dimensional nature of Parkinson's is a motif that runs through many of the studies in this review, and is vividly captured in an intriguing study of Parkinson's, undertaken through the analysis of four novels, in which the authors showed that the disease does not play a 'marginal' role but rather 'encompasses the entire life and constitutes its core' (Van Der Bruggen and Widdershoven 2004, p.295).

Discrepancy between patient experience and clinician understanding: An attempt to shift the medical perception of Parkinson's away from the purely motoric domain is clear from Brod, Mendelsohn et al's study (above), where they cautioned clinicians and researchers against focusing too narrowly on 'medical symptomatology' and 'motor severity scores' (e.g. the Hoehn and Yahr scale)^e as a means of understanding patient experience (1998, p.221). This view is consistent with the findings and recommendations of a Tel Aviv based study (using a structured questionnaire) published the previous year, in which the authors reported a discrepancy between suffering, as reported by patients, and their suffering as perceived by clinicians. In the view of the authors, this arose from a tendency to focus 'excessively' on motor disability and general appearance which then led towards the stereotyping of patient experience (Abudi, Bar-Tal et al. 1997, p.58). This problem of stereotyping is also implicit in Habermann's study focusing on 'middle-aged' persons with Parkinson's (n. 16, aged 42-59, U.S.A.)^f in which she found a 'gulf' between her participants' experience of their bodies and that understood by clinicians, who tended to view symptoms as 'disease manifestations that must be regulated or minimised' (1999, p.205). Furthermore, she found a 'lack of acknowledgment' of individuals' concerns by health care professionals in general,

^e This scale is commonly used for describing in broad terms how Parkinson's symptoms progress and the relative level of associated disability (I have included the table in Chapter 4. See 4.9 below).

^f The 1999 study is based on the same interview material collected for her 1996 study.

and observed that stories of ‘caring, nurturing practices’ were missing from participants’ accounts (1996, p.411). Chiming with Ruth Pinder’s earlier findings, she concluded that the acquisition of ‘experiential knowledge’ was a major demand on her study participants (ibid.) and, in line with Pinder’s proposal for ‘new patterns of interaction’ between patients and clinicians (Pinder 1988, p.85), called for a meaningful exchange of ‘professional expertise’ and ‘experiential gained knowledge’ (1996, p.411, 1999, p.206).

During the course of reviewing the qualitative literature related to Parkinson’s I have been struck by the frequent references to a discrepancy between patient experience and clinician understanding, and this discrepancy has also been noted at the moment of diagnosis (Pinder 1992a, Habermann 1996, Phillips 2006). Pinder, for example, found that diagnosis represented ‘a point of maximum theoretical coherence’ for the GPs she interviewed, whereas for patients receiving the diagnosis of Parkinson’s it was a time of ‘maximum experiential incoherence’ (1992a, p.3). Although not discussing the *moment* of diagnosis in detail, Habermann observed that in her participants’ experience ‘the human significance’ of diagnosis was passed over (1996, p.404). Again, a study undertaken ten years later (n. 11, aged 56-85, U.S.A.) found this still to be the case, despite research demonstrating that ‘quality of life [following diagnosis] was associated with satisfaction of the explanation of Parkinson’s given at the time of diagnosis’ (Phillips 2006, p.368).

The role of acceptance: A number of studies have sought to understand how people adapt to their illness. Perhaps not surprisingly, the need for ‘purposeful’ or ‘increased effort’ has been identified as a key determinant in negotiating the illness experience - physical and social – of Parkinson’s (Marr 1991, p.328, Bramley and Eatough 2005, p.227). Whilst Dakof and Mendelsohn found a ‘substantial variation’ between participants in the way they responded and adapted to their illness (1989, p. 369), Marr’s small study (n. 6, aged 53-79, Canada) found that *effort* pervaded all aspects of her participants’ experience of Parkinson’s. She also found that the effort required to manage Parkinson’s, even at the most basic level - eating, bathing, dressing, or generally moving about - was sustained by two driving factors: an *acceptance* of the diagnosis and the desire to maintain independence and ‘normality’ (1991, p.328). The role of acceptance is complex and a small study (n. 12, aged 64-84, disease duration 1-5 years, U.S.A.) found that maintaining a sense of

continuity with their 'pre-illness' life was central to acceptance and sustaining quality of life (Whitney 2004). On the other hand Habermann found that, whilst the naming of their disease might legitimise 'ambiguous bodily changes' and bring relief to some participants, this 'acceptance' did not preclude an emotional – often angry – response to diagnosis (1996, p.402). Furthermore, in a small study examining the relationship between self-help group membership and coping (n.8, aged 62-86, U.K.), the authors questioned whether some participants' reluctance to join such groups was related, at least in part, to *non*-acceptance of their illness (Charlton and Barrow 2002, p.477). However, a more recent - and larger scale study- (n.87, of whom 41 had PD, U.K.) has suggested that, rather than being a consequence of 'non-acceptance' of their illness, reluctance to attend support meetings (in the case of people with MND as well as Parkinson's) arises from 'tensions of identity': i.e. successful support demands identifying with the other, and yet to do so in the context of these two debilitating and incurable diseases might be highly upsetting (Mazanderani, Locock et al. 2012, p.549).

Gender: Some quantitative research has explored differences in symptom presentation between men and women,¹² but little research has examined, in a comparative way, whether or not gender affects the means by which people with Parkinson's negotiate their illness. One study examining women's experience (n. 19, aged 34-56, Scotland) has highlighted how competency – or perceived competency - can be put under pressure by labile emotions, emotional exhaustion, changes in body image, lifestyle and relationships, and physical fatigue (Fleming, Tolson et al. 2004). In addition, 15 of the women in the study experienced an increased severity of menstrual problems following the onset of Parkinson's. Yet again, their perceptions of interactions with healthcare professionals highlighted incongruities between patient experience and clinician understanding, emphasising the importance of addressing the 'unmet needs' of non-motor symptoms in order to avert 'distress.' When asked about their experience, the women reported that clinical meetings focused on 'drug efficacy and mobility' whereas the 'distressing' problems such as menstruation, relationships and sexual difficulties were 'rarely addressed' (Schartau, Tolson et al. 2003, p.33).

An earlier study, also focusing solely on women, (c. 8 women, aged 35-59, Tel Aviv) found that discrepancies in the understanding of the illness experience

extended beyond the patient and clinical relationship into the public domain. Importantly, the authors found that, distinct from other chronic illnesses, Parkinson's negatively affected both the manner in which the women perceived themselves *and* the way in which they were perceived by others (Posen, Moore et al. 2000). This was attributed to the stereotypes and misconceptions surrounding Parkinson's, particularly the widely held view that it is 'an old person's disease' and also its strong association with cognitive deficiency and decline (ibid. p.87).

Age: Since the first person I interviewed formally for my research was in her thirties, I very quickly came to understand that Parkinson's does not only affect 'older' people, and this is underlined by the two studies cited above in which the majority of the women were diagnosed with 'young onset' Parkinson's.[§] In one of the only studies (quantitative) that I have been able to find that has specifically compared the experience of young-versus older-onset Parkinson's disease, the authors concluded that patients with young-onset PD suffered from 'greater impairment of quality of life' due to social and psychosocial factors. These included loss of employment, disruption of family life, depression and 'greater perceived stigmatisation' (Schrag, Hovris et al. 2003). However, the authors themselves urged caution in assuming 'insight into the differential difficulties' (p.1255) between young and older onset patients since the study relied on self-reporting.

This is an important point to bear in mind given the wide age range of my own participants (36-82), and it has been useful to read that in a small study of 'older women' (n 8, aged 63-80, Sweden) issues of stigmatisation also emerged as an area of particular concern. Women expressed the fear of 'being negatively evaluated in public and receiving negative comments' (Caap-Ahlgren, Lannerheim et al. 2002, p. 93). Importantly, the feeling of 'perceived stigmatisation' arose not from age or cognitive deficiency, but from embarrassment and shame due to hypomimia (masked face); the effect of the disease on participants' ability to speak; and a feeling that they looked 'incompetent' and were therefore perceived by others as 'idiots' (ibid.). In both this study and another examining perspectives on daily living (n. 7 with PD, aged 64-77, & 9 relatives, Sweden) unpredictable fluctuations in both physical and psychosocial competence were found to be connected to social

[§] A person diagnosed under the age of 50 is considered to have 'young onset' Parkinson's.

withdrawal and, not surprisingly, Parkinson's disease was found to affect not only the patient's quality of life, but also that of the family (ibid. & Wressle, Engstrand et al. 2007).

Family and psycho-social issues: Many studies have made passing reference to the impact of Parkinson's on the family and carers. However, Margaret Holloway (U.K.) drawing on data from two earlier studies (the first mixed methods and the second 'mostly qualitative'), has particularly stressed the effects of Parkinson's on the family and carers, finding them frequently to be as disadvantaged and stigmatised as the person with Parkinson's (2007, p.131). Again, she observed that health professionals tended to pay most attention to physical symptoms, corroborating the findings of earlier studies (Marr 1991, Abudi, Bar-Tal et al. 1997, Brod, Mendelsohn et al. 1998), but she emphasised that, for the carers or family, it was the 'social and emotional impact' arising from those physical symptoms that was often of greater significance (ibid.) than the symptoms themselves.

Indeed, it is the social and emotional impact arising from physical symptoms and affecting both the person with Parkinson's and their family that constitutes another important theme running through many of the studies reviewed, including those focusing on very particular aspects of Parkinson's, such as communication changes, sleep disturbance, 'freezing' and dysphagia (difficulty swallowing). Thus, in a small study examining communication changes in people with Parkinson's (n.4 people with PD and 4 partners, aged 60+, U.K.), the author observed that communication changes (brought about by physical impairment as well as fatigue, tremor, diminished attention and memory loss) affected the psychological and social well-being of partners as well as those with the diagnosis (Whitehead 2010, p.36). Similarly, a small study (n.5 men, aged 57-76, U.K.) exploring sleep disturbance^h found that relationships were affected by participants restricting or avoiding activities, giving up hobbies, withdrawing socially and, in some cases, feeling the need to sleep in a separate room or bed (Suddick and Chambers 2010, p.292). The effects of 'freezing' (n. 6, aged 52-77, U.K.) also resulted in people no longer socialising because they had become fearful of falling and lost confidence (Redmond and Suddick 2012, p.173) and the effects of dysphagia (n. 23 men & 14

^h Participants attributed sleep disturbance to age, nocturia, swallowing problems, tremor, restlessness and vivid dreams (2010, p.297).

women, aged 50-88) ‘impinged not narrowly on chewing and swallowing (i.e. the physical symptoms) but on broader practical and social activities surrounding mealtimes.’ It was acknowledged that the act of *listening* to people’s own perception of dysphagia highlighted an incongruence between the ‘lived experience’ of people with Parkinson’s and the ‘mild picture’ gained by health professionals who usually used ‘objective swallowing assessments.’ Consequently, the study revealed that swallowing impairment need not be severe (as had been supposed through ‘objective’ measurements) in order to result in significant psychosocial issues – including ‘feelings of stigma’ - both for the person with Parkinson’s and their carers or family (Miller, Noble et al. 2006, pp. 614 & 617).

As indicated above, only a small number of studies have been specifically designed to let people with Parkinson’s speak freely, on their own terms, about what it means to live with the disease, recognising that accounts are shaped by the illness stage, as well as the social and historical context in which they are told. One exception is Marr’s small study (1991, mentioned above) in which her six participants were invited to describe their life with Parkinson’s disease in an ‘unstructured’ interview. Another exception was a study (n. 23, aged 40-84, Netherlands) undertaken by the Dutch sociologist Gerhard Nijhof in order to find patterns in participants’ interpretations of Parkinson’s disease. He concluded that circa half of his participants interpreted their disease as a problem of shame resulting in their ultimate withdrawal from public life (Nijhof 1995). In a further analysis of the same interviews he found, as in studies before and since, that uncertainty and unpredictability played a key role in people’s experience of Parkinson’s (Singer 1974, Pinder 1988, Caap-Ahlgren, Lannerheim et al. 2002, Haahr, Kirkevold et al. 2011). More particularly, he focused on the interdependence - for some - between uncertainty and a lack of trust, as manifested through a lack of trust in the body (e.g. freezing), ‘the self’ (e.g. loss of self-confidence) and ultimately a lack of trust in the world - i.e. what once felt natural was now concerning to a point that one no longer dared act in that world (Nijhof 1996, p.60).

Although Nijhof’s study is almost 20 years old, these themes of uncertainty, unpredictability and lack of trust continue to resonate in the findings of more recent research, including a study focusing on people living with advanced Parkinson’s (n. 11, aged 47-67, Denmark) which highlighted the degree to which Parkinson’s

altered participants' 'life worlds,' and showed that unpredictability, uncertainty and a lack of trust in the body were the key determinants in their decision to undergo deep brain stimulation (DBS) as a 'last resort' (Haahr, Kirkevold et al. 2011, p.412). Similarly, a recent study (n.14, aged 38-82, U.S.A.) again emphasised the unpredictable nature of Parkinson's, stressing in this case that living with it demands daily negotiations 'in the midst of uncertainty' (Stanley-Hermanns and Engbreton 2010, p.350).

2.7 Incorporating and utilising the literature

While reading and reviewing the extant body of qualitative studies relating to Parkinson's, I have remained alert to the view that the lived experience of illness is socially, culturally and historically contingent, shaped by prevailing norms and values which alter in relation to 'broader social transformations' (Nettleton, p.72). I have, however, been struck by the degree to which findings from earlier studies echo throughout contemporary research, and this has been a useful reminder of the importance of looking to the past in order to understand the present. Indeed, Ruth Pinder might be surprised at how influential her research has been, both in its original aim of redressing the lack of attention given to the 'patient's perspective' in the literature, as well as its role in helping shape and inform later studies, including my own.

The insights offered by the literature have been instructive in a number of ways, helping shape my methodological decisions, study design and analysis. For example, issues raised by Mazanderani et al (2012) in their study focusing on support groups was particularly helpful when I used Parkinson's UK local groups as a means of recruiting participants. Their findings challenged me to think carefully about who might attend a local group and who might not and confirmed the importance of accessing participants through diverse routes. I knew that I wanted my study to be as inclusive as possible and it was therefore important to find a means of capturing the stories of those for whom attendance at such meetings might be 'highly upsetting' (p.549).

Importantly, the qualitative literature has enabled me to gain a fuller and clearer understanding of the clinical features of Parkinson's, as well as draw attention to the importance of the psycho-social aspects of the disease. Having read the literature,

one can be in no doubt that Parkinson's is so much more than a 'movement disorder' and, as highlighted in my review, the multi-dimensional nature of Parkinson's resonates down the years alongside recurring themes such as unpredictability, uncertainty, stigma, social withdrawal, social isolation and a discrepancy between patient experience and clinician understanding. These themes have been an important reference point throughout my own analysis.

At the same time, my study seeks to respond to perceived absences in the literature. For example, Habermann's evocative observation that, in the experience of many of her participants, 'the human significance of diagnosis was passed over' (1996) stayed with me throughout my interviews. Returning to the literature, I found many tantalising references to diagnosis and yet, apart from Pinder's study (1992), the actual moment of diagnosis was discussed only fleetingly. As a consequence I have tried to contribute to the literature by providing further empirical material and discussion around that moment of diagnosis.

Finally, a main aim of this study is to expand the UK based literature on the experience of Parkinson's by using a methodological approach that has not previously been used in an analysis of the illness experience of Parkinson's (see 2.8 below). I therefore hope that this thesis will provide a fresh perspective on Parkinson's by placing participants' stories at its centre and employing narrative analysis methods as a means of interpreting and representing people's stories in differing ways over the course of three data chapters. As will become apparent in my methodology chapter, I have drawn on the work of the sociologist, Arthur Frank, both as a listening device for understanding and interpreting the types of narrative used by my participants, and as a means of structuring my thesis. I have, however, saved any discussion of Frank's work – as well as literature relevant to the analysis of illness narratives – for my methodology chapter.

¹ For example, a search through medical databases for articles featuring “Parkinson’s disease” on one day in April 2013 produced the following results: EMBASE, over 242,000 articles; The Cochrane Library, 59 articles; PubMed, 46,590 articles, and CINAHL 6,849 papers. A more refined search, limited to the years 1997-2007, revealed over 23,000 scientific articles related to Parkinson’s (Fahn, 2009). By comparison, the British Nursing Index, which includes some of the qualitative research undertaken into Parkinson’s, produced 330 papers, the majority of which were aimed at better healthcare practice.

² According to the PUK website ‘We’re the largest charity funder of Parkinson’s research in Europe and we’re leading the way to better treatments and a cure.’ - See more at:

<http://www.parkinsons.org.uk/content/finding-cure-parkinsons#sthash.cRbBL1Rk.dpuf>

³ At that time Professor Andrew Lees was Professor of Neurology at The National Hospital for Neurology, Queen Square, London. He remains “the most cited researcher in Parkinson’s disease” (<http://www.ucl.ac.uk/rlweston-inst/people/ajl>).

⁴ The book ‘Awakenings’ describes Oliver Sacks’ involvement with patients suffering Parkinsonian symptoms after the encephalitis lethargica pandemic (‘sleeping’ or ‘sleepy’ sickness) which started mysteriously c. 1916-17 before disappearing equally mysteriously in 1927. The book explores patients’ reactions ‘brought about by a remarkable new ‘awakening’ drug – L-dopa’ (preface to 1st edition). The 1990 film based on the book stars Robert de Niro and Robin Williams.

⁵ He cited the example of ‘a trisomic albino female of 21,’ and suggests that such a description ‘could as well apply to a rat as a human being.’ Preface to the Folio Edition of ‘The Man Who Mistook His Wife for a Hat’ (1985, pp xi-xii).

⁶ Cecil Todes (1931-2008) was a child psychiatrist who clashed with Anna Freud over the best way to treat disturbed children. He was diagnosed with Parkinson’s at the age of 39 and went on to write about his almost 40 year search for a cure – including the injection of foetal cells in 1988 – in ‘Shadow Over My Brain’ (1990), published after Pinder’s article. According to Oliver Sacks, it was the first account “which brings both perspectives together – that of the patient and that of the doctor.” In an obituary, the Consultant Psychiatrist, Nathaniel Minton (1935-2012) wrote that Todes’ account “should be essential reading for all medical students interested in neurology and for all trainee specialist neurologists.” (<http://www.independent.co.uk/news/obituaries/dr-cecil-todes-author-of-shadow-over-my-brain-867651.html>).

⁷ Bourke-White was an intrepid photographer for Life magazine, whose ground-breaking surgery by Dr Irving Cooper was featured – with photographs – in the June 22, 1959 edition of Life. The final two chapters of her Memoir outline her encounter with Parkinson’s (pp. 358-383). See [Appendix 1](#).

⁸ ‘Ivan’ – A Horizon documentary (Season 21, Episode 6, 03/12/1984) was produced by Jonathan Miller, who also wrote the foreword to Vaughan’s book. Vaughan was responsible for introducing John Lennon and Paul McCartney to each other. He occasionally played bass in Lennon’s first band, the Quarrymen. Diagnosed with Parkinson’s at the age of 35, he died in 1993 at the age of 51.

⁹ This documentary was controversial. According to Miller, Vaughan’s experimentation alienated some neurologists as well as members of the PD Society, who argued that his case was ‘atypical’ and that his film appearance was “misleading and alarming.” Vaughan, I. (1986). Ivan: Living with Parkinson’s disease.

¹⁰ ‘Pondering on Parkinson’s’ cited at the outset of this literature review is one such self-published account. For an overview of self-publishing see the magazine Poets & Writers, November/December 2013 http://www.pw.org/content/notable_moments_in_selfpublishing_history_a_timeline

¹¹ Healthtalkonline was founded for patients by the GP Ann McPherson (1945-2011). Visitors to the site can watch, read about or listen to more than 2000 people’s experiences of living with over 60 health-related conditions and illnesses, as well as use the website as a source of “reliable information about specific conditions, treatment choices and support.” See: <http://www.healthtalk.org/peoples-experiences/nerves-brain/parkinsons-disease/overview>

¹² For example, see Miller, I. and A. Cronin-Golomb (2010). "Gender differences in Parkinson's disease: Clinical characteristics and cognition." *Movement Disorders* 25(16): 2695-2703.

2.8 Table of UK based qualitative research - PD (1988-2014)

Authors/Year	Aim, design & methods	Findings	Comments, strengths & limitations
<p>1. Pinder, R. (1988)</p> <p><i>"Striking Balances: Living with Parkinson's Disease"</i></p>	<p>Explore subjective feelings and attitudes of people with Parkinson's.</p> <p>39 interviews (c. 4 per person) with 10 people with Parkinson's over a 10-month period. 9 out of the 10 were members of the Parkinson's Disease Society. Talks lasted c. 1½ hours and revolved around 'broad topics' accompanied by an Interview Guide.</p> <p>Analysis undertaken through lens of symbolic interactionism.</p> <p>Concerned with how people interpreted and gave meaning to their lives rather than objective 'reality.'</p>	<p>Chronic illness results in a complex balancing act. Weighing up options is socially patterned. Managing chronic illness is 'firmly wedded' to the social context in which it is experienced.</p> <p>People have the capacity to define and grapple with their environment. Faced with uncertainty and unpredictability, problems were actively defined and redefined. She noted that many people seemed to try and carry on 'as normally as possible.'</p> <p>The availability (relatively new at that time) of Levodopa added complications a) because of adjustments needed to medication as time passed; b) ceasing to be effective; c) increased longevity brought social, medical and biographical complications.</p>	<p>It is still interesting to read this study over 25 years later – particularly with regard to developments in treatment and with regard to her view that the case of Parkinson's highlighted the need for a more participatory model of information sharing and decision making.</p>
<p>2. Pinder, R. (1992a)</p> <p><i>"Coherence and incoherence: doctors' and patients' perspectives on the diagnosis of Parkinson's Disease"</i></p>	<p>To explore how a group of GPs conceptualised the task of diagnosing patients with Parkinson's disease.</p> <p>To explore the impact of diagnosis on a group of patients.</p> <p>To emphasise meaning, interpretations and experience.</p>	<p>Diagnosis was a point of maximum experiential incoherence for patients.</p> <p>For GPs, diagnosis was a positive moment – a point of maximum theoretical coherence enabling prediction and informed management.</p>	<p>In the UK, GPs are now expected to refer people they suspect of having PD to a neurologist for diagnosis (NICE, 2006) which opens up a different set of questions re how the doctor relates to the patient's diagnosis and shifts the potential for 'coherence' to the neurologist.</p>

Authors/Year	Aim, design & methods	Findings	Comments, strengths & limitations
<p>3. Pinder, R. (1992b)</p> <p><i>"Striking Balances: Detachment or Empathy in the Management of Parkinson's Disease?" -</i></p>	<p>(Part of the above study).</p> <p>Examined four areas from 18 interviews, where GPs expressed anxiety and uncertainty in responding to their patients with Parkinson's.</p> <ol style="list-style-type: none"> 1. Sustaining care over time 2. Accepting patients cannot be cured 3. Managing the task of just 'being there' for patients 4. Responding to patients with communication impairments. 	<p>3 main responses</p> <ol style="list-style-type: none"> 1. Detached approach 2. Counselling-oriented approach 3. Active commitment to empathising <p>Pinder found GPs were all engaged in striking <i>acceptable</i> balances for themselves between detachment and empathy. The way in which doctors did this varied according to personality, physical and emotional stamina.</p>	<p>This would be a fascinating study to undertake (repeat) with consultant neurologists who are also involved in the long term care of the chronically ill.</p>
<p>4. Charlton, G.S. & Barrow, C.J. (2002)</p> <p><i>"Coping and self-help group membership in Parkinson's disease: an exploratory qualitative study."</i></p>	<p>Exploratory qualitative study to establish the effects of Parkinson's disease on participants' lives and whether or not self-help group membership was related to coping methods.</p> <p>Semi-structured interviews with 8 participants of whom 4 belonged to a self-help group and 4 did not.</p> <p>Thematic analysis</p>	<p>All participants experienced losses of physical and mental functioning, independence, self-identity and future and were fearful of further losses. The study reported differences between members and non-members in coping style:</p> <p>Members – showed acceptance of disease and incorporation of it into everyday life. Self-help group a source of support.</p> <p>Non-members – coping relied upon denying the disease a central role and maintaining a 'normal' life. Self-help group was seen as a source of distress. Suggests that some people use coping methods that cannot be sustained in the context of self-help group membership.</p>	<p>Small study – not necessarily representative.</p> <p>Relationship between one of the authors and participants who were members of a self-help group was not explicit.</p> <p>Claimed that they had used 'extensive quotations' that would enable the reader to judge the 'credibility of the analysis.' In reality, quotations were few and may simply have been selected to illustrate themes.</p> <p>As an exploratory study, it usefully raised questions that might feed into further research. In particular, the question of how best to support – psychologically - those people who do not wish to join a self-help group.</p>

Authors/year	Aim, design, methods	Findings	Comments, strengths & limitations
<p>5. Fleming, V., Tolson, D., & Schartau, E. (2004)</p> <p><i>"Changing perception of womanhood: living with PD"</i></p> <p>(Also reported in <i>Nursing Standard</i> under the title <i>"Parkinson's disease: the effects on womanhood"</i> Schartau et al (2003))</p>	<p>Commissioned by Parkinson's Disease Society (2001): Understand the experiences and adjustments made by women with PD in relation to womanhood.</p> <p>Understand each participant's definition of 'womanhood.'</p> <p>Multiple case study design involving 19 women participants, mean age 44, age range 34-56.</p> <p>Stories were told through a combination of individual interview, group interview, reflective diary, reflective tapes and creative writing.</p> <p>Analysis used a framework of Intrapersonal, Inter-personal, Extrapersonal, Metapersonal health.</p>	<p>Four themes were reported:</p> <p><u>Intrapersonal health</u>: Labile emotions, body image and journeying through the disease</p> <p><u>Interpersonal health</u>: Relationships, Sexual relations and increasing dependence.</p> <p><u>Extrapersonal health</u>: Protecting & being protected, good mothers/ grandmothers, friendships and lifestyle.</p> <p><u>Metapersonal health</u>: Isolation</p> <p>*Desire of participants to be 'good' mothers or grandmothers in an attempt to normalise PD? *Dread of the future, especially increasing dependence.</p> <p>* Shock of diagnosis and implications for health professionals * Need for proactive rather than reactive support.</p>	<p>The authors acknowledged the sensitivities involved in undertaking research of such a 'personal nature.'</p> <p>However, there was no acknowledgement or reflection on how the interviewers/researchers may have affected the interview process.</p>
<p>6. Bramley, N. & Eatough, V.(2005)</p> <p><i>"The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study"</i></p>	<p>Idiographic Case Study using Interpretative Phenomenological Analysis (IPA).</p> <p>One participant, aged 62, diagnosed with PD at 44.</p> <p>3 semi-structured interviews - analysed according to 2 'super-ordinate' themes: 'mind and body' and 'self and agency.'</p>	<p>Living with Parkinson's engenders a complex relationship between mind & body and has a profound effect on the sense of self. Describes daily challenges associated with Parkinson's; the cyclical nature of the disease and treatment; the need for 'purposeful' effort; the disruption of sense of self and agency yet, over time, the incorporation of the illness into a sense of self. In line with other studies, this case study illuminates issues that represent persistent challenges to the individual, which are not acknowledged by physician.</p>	<p>This case study approach offered a 'holistic' understanding of one person's experience of Parkinson's – so often lacking in the literature.</p> <p>No reference to how long the interviews were, or the time period over which they were conducted. No mention of ethics clearance. Despite the 'holistic' nature of the participant's illness experience, no reference was made to the possible influence of the researchers during data collection.</p>

Authors/year	Aim, design, methods	Findings	Comments, strengths & limitations
<p>7. Miller, N., Noble, E., Jones, D., & Burn, D. (2006)</p> <p><i>“Hard to swallow – dysphagia in Parkinson’s disease.”</i></p>	<p>Explore the feelings and attitudes towards living with (possible) changes in swallowing.</p> <p>Semi-structured interviews with a purposive sample of 37 individuals 14 women and 23 men (and their carers).</p> <p>Content analysis using computer programme – key themes derived from categories.</p>	<p>Swallowing impairment need not be ‘severe’ (according to scales of measurement) in order to cause significant impact on people with PD as well as their carers.</p> <p>Physical changes (affecting chewing, swallowing and manual skills) had profound psychosocial consequences, ranging from fear of choking to a severely reduced social life.</p> <p>Adjustments might be made, but had implications (negative) for carers – time for preparation & organisation.</p>	<p>Study very much about raising awareness of potential issues.</p> <p>Helpful for encouraging attention to individuality of experience and for highlighting the need for dysphasia not to be seen solely in functional terms.</p> <p>Wider repercussions of swallowing changes should be probed – e.g. effects on self-esteem, enjoyment, family dynamics, fatigue, social life etc.</p>
<p>8. Williams & Keady (2008)</p> <p><i>“‘A stony road... a 19 year journey’: ‘Bridging’ through late-stage Parkinson’s disease”</i></p>	<p>Longitudinal study focusing on the experiences of older people with PD and their families during late-stage disease.</p> <p>A grounded theory approach to generate new theoretical insights in order to inform practice.</p> <p>69 interviews with 13 participants over 10 months.</p>	<p>Importance of biography in accommodating long-term conditions.</p> <p>The authors found a reluctance to broach the future.</p> <p>Importance of reciprocal relationships.</p> <p>Support offered (e.g. by health professionals) does not match requirements.</p> <p>Need for more pro-active approach to the provision of respite care.</p>	<p>A small study with a very clear aim. However, it lacked reflection on the influence the author, as a SALT, may have had on participants’ accounts. Eligibility for participation was dependent on having a family carer (usually a spouse). All were recruited from within one Movement Disorder Clinic – thus one particular model of healthcare may have shaped their experience. Both authors were from nursing backgrounds.</p> <p>Commonalities were discussed but there was limited discussion re differences. Sparse elaboration of how the results were actually shared, modified and tested (as suggested in abstract)</p>

Authors/year	Aim, design, methods	Findings	Comments, strengths & limitations
			<p>Authors made an assumption that breaks in relationships come in the late stages of PD (this was not my experience). Article lacked reflection on the possible influence of researchers (nursing backgrounds).</p>
<p>9. Cook, N., McNamee, D., McFetridge, B., & Deeny, P. (2010) (Northern Ireland)</p> <p><i>"Experiences of people with Parkinson's disease and their carers of a specialist nursing service."</i></p>	<p>Perceived role of the PD nurse specialist aimed at clarifying the role and making recommendations for enhancing the role and improving services.</p> <p>Mixed methods using questionnaires and semi-structured interviews (8 participants with PD and 8 carers).</p>	<p>Parkinson's nurse plays a pivotal role in enabling people with PD and their carers to live with the condition.</p> <p>There was high satisfaction re the nurse's role in helping people with PD and their carers understand and cope with side effects. The nurse was seen as an important link and contact person.</p> <p>Least satisfied with provision of information re respite care.</p> <p>Identified the need for review of the number of specialist nurse posts & accessibility in both hospital and community settings.</p>	<p>Possible selection bias given that sampling for the questionnaires came from the Parkinson's nurse caseload.</p> <p>Researchers were all nurses/lecturers in nursing. No reference to how this may have affected responses of participants. The response rate was low (24%) and the reason for this was not made known to the researchers.</p> <p>Ethical procedures within the researchers' health trust meant that there may also have been selection bias in the qualitative study as access to patients and carers was organised by a professional involved in their health care.</p>
<p>10. Suddick, K., & Chambers, S. (2010)</p> <p><i>"The lived experience of sleep disturbance in people with Parkinson's disease."</i></p>	<p>Exploratory study of the lived experience of sleep disturbance in a group of men with Parkinson's disease (PD)</p>	<p>Themes that emerged regarding sleep disturbance in PD were:</p> <ol style="list-style-type: none"> 1. 'good and bad' sleep 2. a worsening journey 3. the experience of uncertainty 4. the experience of loss 	<p>The study participants were all male, married and recruited from one local support group within the UK.</p> <p>The report is written in the third person and it was not clear which of the two authors undertook the interviews and</p>

Authors/year	Aim, design, methods	Findings	Comments, strengths & limitations
	<p>Interpretive phenomenological approach using a convenience sample of five people from the UK with PD participated in interviews in 2007–2008.</p> <p>One interview not recorded - technical hitch – therefore ‘remembered’ and written down after. Two interviews were undertaken over the telephone.</p> <p>Interviews were transcribed and data thematically analysed.</p>	<p>Sleep disturbance and ‘good and bad’ sleep, had significant implications for the person with PD <i>and</i> their carer. People with PD may accept or fight their sleep disruption, use, restrict, or avoid activity, and give up hobbies and sharing the marital bed.</p> <p>Sleep disturbance meant being part of a ‘worsening journey,’ and experiencing loss and uncertainty.</p> <p>These may be inseparable essences of living with a progressive neurological condition.</p>	<p>there was no discussion of the potential for bias (one author was a Physiotherapist).</p> <p>This study was specifically aimed at health professionals and concluded that organised programmes to address sleep disturbance were required. One of the authors was a physiotherapist and the study appears to have been undertaken very much through the lens of a therapist. The authors intended their findings to support the work of specialist Parkinson’s nurses.</p>
<p>11. Whitehead, B. (2010)</p> <p><i>"The Psychosocial impact of communication changes in people with Parkinson's disease"</i></p>	<p>Explore the perspectives of individuals with Parkinson’s disease and their spouses on their experiences of living with communication difficulties as a consequence of the disease.</p> <p>Thematic analysis of semi-structured interviews with 4 people with Parkinson’s & 3 spouses. Interviews were undertaken separately.</p>	<p>Communication changes significantly impacted on both the individual’s and the spouse’s psychological and social functioning.</p>	<p>The author is a speech and language therapist (SALT) and advocated a more multi-disciplinary approach to support for patients and families affected by Parkinson’s. The research was, in part, to encourage earlier referral to the SALT services by specialist nurses.</p>
<p>12. McLaughlin, D., et al. (2011) (Northern Ireland)</p> <p><i>"Living and coping with PD: Perceptions of informal carers"</i></p>	<p>Exploratory qualitative study to understand the experience of informal* family caregivers of people with Parkinson’s *(i.e. care at home provided by a family member over the age of 18).</p>	<p>Immense emotional, social and financial burden of care-giving role. Lack of support. Accessing information and financial advice problematic. Yet – determined and stoic in approach to caring.</p>	<p>Recognised this was a study ‘in one context at one time’ and detailed findings may not be generalizable. Very little explanation of how analysis was conducted – ‘a framework was used’ (p.178).</p>

Authors/year	Aim, design, methods	Findings	Comments, strengths & limitations
	<p>Convenience sampling of 26 (17 women and 9 men). Majority (n. 21) were over 55 years of age. Duration of caring role, 2 – 20 years.</p> <p>Content analysis of semi-structured, audio-recorded interviews, lasting 30-60 minutes.</p>	<p>Misconception of palliative care as cancer care leading to concern own health may suffer.</p> <p>Lack of opportunity to prepare for and discuss their ongoing role.</p> <p>Perceived communication from consultants as insensitive.</p>	<p>Potential for bias, given recruitment relied on adverts and support groups.</p> <p>Those carers outside such support systems may have had a different perspective.</p>
<p>13. Attard, A. & Coulson, N. (2012)</p> <p><i>'A thematic analysis of patient communication in Parkinson's disease online support group discussion forums.'</i></p>	<p>Examine positive and negative aspects of online communication through thematic analysis of patient-to-patient communication in PD online support group discussion forums.</p> <p>Data collected from 4 forums.</p> <p>Thematic analysis conducted through an 'essentialist/realist' framework.</p>	<p>Positives of online communication included the ability to share experience and knowledge; form friendships; support each other in coping with the challenges of PD</p> <p>Negatives found that the online experience was compromised by a lack of replies; Parkinson's symptoms; a lack of personal information; fragility of online relationships and misunderstandings and disagreements.</p>	<p>The authors identified that they could not be sure that all messages sampled were posted by people with PD.</p> <p>People with positive experience were more likely to contribute than those with a negative experience Interpretation – without non-verbal cues – may have been inaccurate and patients themselves were not asked about their experience of online support.</p> <p>Meaning of 'essentialist/realist' framework unclear.</p>
<p>14. Mazanderani et al. (2012)</p> <p><i>"Being differently the same: The mediation of identity tensions in the sharing of illness experiences" (MND & PD)</i></p>	<p>Explore how people with different chronic and/or terminal illness use or do not use different forms of peer support – in particular online ones – as a source of health –related experiential knowledge.</p> <p>Secondary analysis of 87 interviews (46 with people with MND; 41 with people with PD) – originally undertaken for</p>	<p>7 themes emerged, of which 3 were discussed in the article.</p> <p>Tensions of identity, peer support and 'seeing others' – i.e. for others' experience to be meaningful, people need to identify with one another and yet to do so can be highly upsetting.</p>	<p>The authors raised many questions for suggested future research.</p> <p>Although discussing both MND and PD, the focus was more on the former.</p> <p>The paper focused on contradiction and yet lacked discussion of any perceived difference between the two conditions.</p>

Authors/year	Aim, design, methods	Findings	Comments, strengths & limitations
	healthtalkonline project.	<p>‘Being differently the same’ – allows people to overcome their initial resistance to seeing and sharing disease experience and to negotiate identity tensions.</p> <p>Mediating experience – similarity & difference are not fixed categories. Value others’ experiences due to ‘shared embodiment’ of a condition; others’ experience ‘irrelevant’ because everyone is ‘different.’</p>	
<p>Redmond, L. and K. Suddick (2012). <i>"The lived experience of freezing in people with Parkinson's: an interpretive phenomenological approach."</i></p>	<p>Explore the experience of freezing for people with PD where there is currently limited understanding.</p> <p>Methods: An interpretive phenomenological approach through semi-structured interviews (5 on the telephone) with a purposive sample of 6 participants.</p>	<p>Freezing was experienced as an entity, which was unpredictable and uncontrollable. Its impact was a heightened physical awareness, and a feeling of separation and alienation from one's body. This affected the person's emotions and heightened the link between their emotional and physical self.</p>	<p>Authors felt their findings highlighted the need for further research into the lived experience of people with Parkinson's. Their study is a starting point for a greater understanding of freezing. They advocated further work may to explore and broaden this concept.</p>

CHAPTER 3: METHODOLOGY, METHODS & RESEARCH DESIGN

“There is no such thing psychologically as ‘life itself’: At very least, it is a selective achievement of memory recall; beyond that, recounting one’s life is an interpretive feat.”
(Jerome Bruner, 1987)¹

“We only come to look at things in a certain way because we have adopted, either tacitly or explicitly, certain ways of seeing”
(Silverman, 2005)²

As outlined in my introduction, this thesis is one of four studies undertaken as part of the Wellcome Trust funded LABTEC project, the aim of which has been to examine the social impact of recent developments in neuroscience. It contributes to the overall project by giving voice to the patient experience when faced with a serious neurological disease – Parkinson’s. In order to ensure that the distinctiveness of my participants’ voices is heard, I have situated analysis within the field of dialogical narrative inquiry, with particular reference to the work of Arthur Frank (Frank 2005, 2010, 2012). At its simplest, dialogical narrative inquiry, or analysis (DNA) ‘takes particular interest in learning from storytellers,’ but also emphasises that any analysis should involve careful examination of the relationship between the story, the storyteller and the listener (2010, pp. 16-17). Importantly, it challenges the ‘pre-defined’ nature of much qualitative research (mentioned in the previous chapter) by aiming to ensure that interviews are not conducted solely to garner quotations that might ‘illustrate a theme that the researcher has located in the data’ (2005, p.970). Rather, at its core, DNA seeks to ascertain how lives are ‘affected by stories’ (1995, p.155).

3.1 Chapter outline

Prior to explaining my methodological approach in detail, I start by outlining the original intention of this study and the reasons it became necessary to alter its focus. I then present a brief outline of preparatory work undertaken to facilitate the study, including ethics approval, initial recruitment preparation, and some reflections on researcher identity and the impact it might have on my role as ‘listener.’ The stories arising from my participants’ interviews are, of course, key to this study, but methodologically it has felt important to include some of the ‘peripheral’ stories that

have shaped its design. I have therefore continued the chapter by briefly outlining a story that played an important role in guiding me towards a methodological approach true to my epistemological viewpoint. I follow this with a more detailed discussion explaining the decision to adopt an approach grounded in Frank's understanding of dialogical narrative analysis (DNA).

Before explaining *how* I implement DNA within this study, I have detailed the methods used in designing a study suited to this methodological approach. For sake of clarity, I have taken a broadly chronological approach where possible. I then 'interrupt' the chapter with a story within a story. This is not only to illustrate the non-linear nature of designing a study such as this, but also to highlight the iterative - as well as reflective - nature of this research and the importance of participants' voices in continuing to shape and endorse my methodological approach once I had begun the interview process. I then return to my research design and some of its 'unanticipated' aspects before detailing my approach to the analysis of my transcripts. I discuss how I perceive my role as a researcher and the means by which I have opened up analysis in general. I then conclude this chapter by outlining the different approaches I have undertaken for each of the three ensuing chapters that work with my participants' stories.

The original intention of this particular study was to record and analyse the views towards medical research of people diagnosed with Parkinson's disease (PD) *and* Motor Neurone Disease (MND), two differing but both degenerative diseases. However, following the transmission on BBC 2 of "Terry Pratchett: Choosing to Die" (June 2011) in which viewers saw Peter Smedley^a visit the Dignitas Clinic in Switzerland in order to end his life, the MND Association (MNDA) decided it needed to respond in a practical way to the intense debate generated by this documentary. I had just received ethical approval (September 2011) to proceed with recruitment for my study when I discovered that the MNDA had commissioned a large-scale piece of qualitative research aimed at eliciting the views of people with MND towards Assisted Dying.³ After extensive discussion with my supervisor, Professor Bobbie Farsides, and the Director of LABTEC, Professor Clare Williams, we reluctantly came to the decision that to continue with my study in its original

^a Peter Smedley was diagnosed in 2009, two years before his assisted suicide.

form might lead to the over-researching of an already small study group. However, any sense of disappointment at having to limit my focus was rapidly mitigated by the enthusiasm shown for the study by people in the Parkinson's community. By 'community' I here mean people with a shared interest in Parkinson's, including people with Parkinson's themselves, their carers, Parkinson's specialist nurses and neurologists, as well as members and employees of charities such as Parkinson's UK and Cure Parkinson's Trust.

3.2 Preparatory work

Prior to recruiting participants for this study, I gave considerable thought to its design, gaining approval both from my institution's Research Governance and Ethics Committee as well as the National Research Ethics Service (NRES – South East Coast).^b In hindsight, it was a hugely important time for beginning to make links with people actively involved in the world of Parkinson's (and MND). It provided the opportunity for me to develop and clarify my thinking and played a vital role in prompting me to prepare for the actuality of meeting participants. In particular, it helped me think through not only how I was going to recruit participants, but also reflect deeply on the consequences of asking people to tell me about their experience of living with illnesses that are both degenerative and incurable. It was an important period for considering the ethical implications of interviewing people who, as implicit from my literature review, may be deemed vulnerable as a consequence of their illness; who may have communication difficulties, may be depressed, or who may suffer from symptoms or become fatigued during the course of the interview. Following the decision to focus solely on Parkinson's, I contacted the NRES and received approval for the amendment. This was confirmed in the April of 2012.

Gathering material for a research study involves a series of inter-related activities and does not proceed in a linear manner (Cresswell 2007). Having received ethics approval to proceed, I began recruitment for this study in September 2011. Prior to recruitment, I had made contact with Parkinson's UK at both national and local level and met with specialist Parkinson's Nurses. Once ethics approval was confirmed, I arranged to attend and observe local Parkinson's UK (PUK) group meetings and

^b See end of appendices section for a copy of the letters of approval.

was fortunate to be offered the opportunity to observe clinics, speak with a group of GPs, and interview a neurologist specialising in Parkinson's as well as a Speech and Language therapist (SALT) (discussed later).

As outlined above, I shall first explain how I came to choose the methodological approach I have adopted in this study and, having done so, how I prepared myself to carry out the data collection and analysis required. I have taken the decision to include - sparingly - the voices of a few participants earlier in my thesis than is perhaps the 'norm.' This is in recognition that, although it is the illness stories of participants that are central to this study, the decision of how best to capture and represent these stories has its own story to tell. Not to include the occasional voice of my participants in this methodology chapter would be to silence the important role that they have played in shaping the decisions I have taken.

3.2.1 Researcher preparedness

In conducting this study, I have found it helpful to draw on my previous experience working for Portage, a home-based educational support service for pre-school children with additional needs and their families.⁴ This involved working with families at a time when their child was either awaiting or had just received a diagnosis or, occasionally, working with children for whom there might never be a definitive diagnosis. As a consequence I gained experience of working with children with a wide range of diagnoses, perhaps the most serious of which was Rett syndrome. Other conditions included Ataxia, visual impairment, severe autism, Down syndrome, Cerebral Palsy, Specific Language Impairment, Williams syndrome and Prader Willi syndrome.

The initial meeting with the child and parent took place within their home (as did the ensuing meetings) - and necessitated a delicate exploration of what the child was able - or not yet able - to do. Thus I was meeting parents whose lives had been unexpectedly turned upside down by the - often unanticipated - disability of their child and whose futures were, as a consequence, riven with uncertainty. I was working with people from all walks of life, in occasionally very challenging circumstances. It was therefore of paramount importance to establish a mutual trust from the outset, ensuring that everyone felt at ease and comfortable with my being in their home. My ability to achieve this has doubtless been influenced and helped by

my own experience. My younger son was diagnosed a little before his seventh birthday with a number of conditions, including autism, and I have my own story of living through years of uncertainty. The diagnosis, when it came, simply confirmed that the uncertainty would continue: there is no cure for autism.

While working for Portage it was, inevitably, through the lens of my own story and experience that I interpreted the actions and views of the parents with whom I worked, whilst trying to remain mindful of the myriad reactions and responses they may have to what - on the surface - appeared to be an experience comparable to my own. Similarly, in undertaking this piece of research it has been equally important to put participants at ease, especially those for whom the interview was the point at which we first met (I had met some people prior to their participation, e.g. at clinics or PUK support groups). Bearing this in mind, and reflecting on how participants may have perceived my role as researcher, they met a healthy, female, mature student who, now in her 50s, has accumulated experience of life both within and outside her own society and culture.^c I am not medically qualified (something I emphasised to all participants) and therefore they met someone who was not part of a system involved in their medical care, nor part of a system offering help and advice, such as one of the Parkinson's charities. I was external to their typical daily lives.

3.2.2 In the beginning: first meeting

When I started this research I came to it with no personal experience of Parkinson's other than the vague memory of a friend of my parent's deteriorating rapidly, in his later years, under the combined clutches of Parkinson's and dementia. I knew that he had had a tremor and that he had had difficulty walking. Other than that, I knew very little about the manifestations of Parkinson's, and even less about what it must mean to someone to be diagnosed with this neurological, degenerative condition. I think I assumed it was a disease of old age. I knew little about its history or the man after whom it was named.

^c I spent more than 12 years working overseas in developing countries (Asia and the Pacific), latterly as a Programme Director for Voluntary Service Overseas (VSO).

To my amazement, only a month after my official start date, while telling someone about the new turn of events in my life, a woman approached me. She explained that she had overheard me mention that I was doing a study about Parkinson's and could she help? She had been diagnosed with Parkinson's eight years previously. Without ethics approval and still unclear as to the best methodological approach for this study, I arranged to meet Sheila informally.

This informal meeting helped me gain initial insight into Parkinson's, as mediated through her experience. It confirmed that, even though she held views on medical research, the latter did not feature prominently in how she had experienced and managed her life since diagnosis. She was, however, very keen to have her voice heard, commenting on how good it had felt to 'have a chance to talk without anyone responding, telling me what to do, how to think or how to solve problems.' She told me she really liked the idea of 'giving a voice to ordinary people – not celebrities.' She also remarked that it was good to talk to somebody who was not an 'interested party,' such as 'someone from a pharmaceutical company or working in the health system.'

3.3 Finding a methodological approach

From my initial reading I already knew that it was not only older people who developed Parkinson's. As I sat across from Sheila in our informal meeting, observing her discomfort and rolling dyskinesia,^d hearing her voice fade occasionally, and listening to the deep impact a diagnosis of Parkinson's had had on her life, work and relationships, I was confronted with the stark fact that this was a woman only two years older than me. She was 53. I was 51. She had already lived with the effects of this disease for eight years and was coming towards the end of what, she explained, is known as 'the honeymoon period.'

By providing me with a real rather than hypothetical situation on which to reflect, Sheila provided me with a valuable starting point when, a month after my meeting with her, I embarked on a week of seminars and workshops about Qualitative Research (QR). In hindsight, it was this meeting with Sheila, combined with

^d Dyskinesia manifests itself through involuntary muscle movements that may look like 'an uncoordinated dance.' See: <https://www.michaeljfox.org/understanding-parkinsons/living-with-pd/topic.php?dyskinesia>

discussions and helpful leads suggested during the QR week, which proved seminal in helping me formulate the approach I have undertaken in my research.

As a consequence of meeting Sheila, I knew that I could not be true to my participants or to myself if I undertook interviews and wrote about them as though I had not been present. I was affected by her story and realised that, methodologically, I would need to acknowledge within my thesis not only the lens through which I viewed and interpreted any stories that would be forthcoming, but also the impact of any story upon me. Moreover, in accordance with Mishler's view that narratives emerging from interviews are constructed jointly by the interviewer and participant, I must recognise the impact of *my* presence on participants and therefore upon the course of the interview (Mishler 1986).

During the QR week, I was advised to read Laurel Richardson's work. I found that I was in strong agreement with her view that qualitative research should not simply be about 'writing up at the end,' but rather should use writing itself as a method of knowing; of discovery and analysis; of finding out about oneself and one's topic (Richardson 1994, p.516). Furthermore, I found myself in sympathy with her opinion that qualitative research should not require researchers and writers to 'silence their own voice [or] view themselves as contaminants' (Richardson 2000, p.925).

Implicit in this is Donna Haraway's contention that researchers should not pull "the God trick" by writing in the anonymous third person (Haraway 1988, p.587), a point that is also elaborated by Gilgun. She worries that many qualitative researchers, despite having 'an array of choices in how to write up their research' [nevertheless] 'write in distanced, third-person voices and give short shrift to the voices of informants, as if neither they nor their informants were part of the research.' This is seen as ethically suspect, since 'omitting the voices of authors and informants perpetuates a form of silencing' (Gilgun 2005, p.256).

Consequently, as mentioned from the outset, my voice appears within this thesis. However, throughout I have tried to maintain a balance between my voice, as researcher and author, and the voices of my participants. At the same time, the length of thesis permitted, together with the methodology I have felt best suited to representing the illness stories of my participants, mean that I have also had to take

difficult decisions over whose voices to bring into the foreground and whose voices to assign to a background role at different stages of the study. Nevertheless, my central aim has always been to keep my participants at the centre of this study, in no way giving ‘short shrift’ to their voices.

3.3.1 Narrative approach: the choice is made

‘A primary way individuals make sense of experience is by casting it in narrative form’
(Riessman, 1993)

‘There is evidence to indicate that through examining the particular significance of a person’s illness it is possible to break the vicious cycles that amplify distress.’
(Kleinman, 1988)

There is a burgeoning literature on qualitative research and even though it may be true that ‘doing research requires discovering the method appropriate to that investigation’ (Frank 2010, p.72), one has only to read “Five Ways of Doing Qualitative Analysis” to understand that the same written and interview data can be understood, as well as presented, in many different ways (Wertz, Charmaz et al. 2011). As Mishler has pointed out, ‘different researchers may tell different stories about what they claim are the same events in people’s lives’ (2004, p.101).

In order to discover the method ‘appropriate’ to my investigation, I read and discussed ideas widely and found myself being drawn again and again towards the field of narrative inquiry. As highlighted in my literature review, much of the qualitative research relating to Parkinson’s has been undertaken by health professionals in order to inform practice within the health or voluntary sectors. Many of the studies have adopted an approach whereby ‘themes are identified and then illustrated with quotes from across the interview data set’ (Bury 2001, p.281). As a consequence, ‘snippets of response [are] edited out of context’ and the ‘lived experience’ of participants is fragmented into ‘thematic (code-able) categories’ in the researcher’s attempt to ‘control meaning’ (Riessman 2001, p.2).⁵ Lost, in the analysis, are the sequential and structural aspects of narrative accounts (1993, p.3). And yet it is through narrative that a person might ‘reconstruct’ their own life story, and give meaning to events that have the potential to ‘disrupt’ and change the course of a person’s life (Bury 1982, Williams 1984, Hyden 1997).

I subscribe to the view that ‘any methodological standpoint is, by definition, partial, incomplete, and historically contingent’ (Riessman 2001, p.24) and that one way of addressing this methodological flaw is to encourage a ‘diversity of representations’ (ibid). Given the perceived importance of narrative as a means of exploring different aspects of chronic illness, it is noticeable that, in the context of research into the lived experience of Parkinson’s, personal narratives and their analysis are largely absent from the qualitative literature.

I here take personal narratives to be understood as ‘talk organised around consequential events’(Riessman 1993, p.3). They are the means by which the ill person orders and coheres the experience of their illness and what it means both to them and ‘significant others’ (Kleinman 1988, p.49). At the level of medicine, ‘narrative contributions’ can be seen as vital for the ‘trustworthiness of medical ethics,’ and Rita Charon argues that any clinical encounter requires ‘that which only narrative knowledge can give: the coherence, the resonance, and the singular meaning of particular human events’(1994, p.261). In the context of this research, however, the importance of my participants’ illness stories lies in their ability to move beyond the realm of the clinical encounter. The study aims to give voice to stories that might not otherwise be heard, opening up dimensions of their illness lived outside the immediacy of ‘patient hood’ (Frank 1995, p.156).

Part of the appeal of narrative analysis lies not only in the fact that it ‘takes as its object of investigation the story itself’ (Riessman 1993, p.1) but also that the story is ‘taken as a whole’ and ‘set in the context in which it has been generated and told’ (Bury 2001, p.281). This approach opens up ‘forms of telling’ and invites the analyst to ask ‘why was the story told *that way*?’(Riessman 1993 p.2). Whilst, in any representation, there will be an ‘inevitable gap between the experience [...] and any communication about it’ (p.10), narrative inquiry seeks both to acknowledge as well as bridge this inevitability. It has felt especially important to try to narrow this ‘inevitable gap’ knowing that, for many of my interviewees, participation in this study was motivated by a strong desire to be ‘understood’ - not only by medical professionals, but also by family, friends, and members of the public in general. I am nevertheless cognisant that some participants questioned whether it would ever be possible for anyone - other than fellow sufferers – fully to understand their ‘lived experience’ of Parkinson’s.

Meeting and speaking at length with Sheila in the early stages of designing this study, and then interviewing her ‘formally’ a few months later, showed me that, as the narrator of her illness story, she was not only making choices about what to ‘divulge’(Riessman 1990, p.1197) but also constructing an ‘ordered account from the chaos of internal experience’ (Josselson 2011, p.225). Although undertaken only a few months apart, these two meetings helped me observe how research participants become ‘the historians of their own lives’ and how, according to Mishler, ‘they tell and retell their stories in variant ways and, thereby, continually revise their identities’(2004, p.101). Furthermore, the two meetings aided my insight into the view that stories, are ‘edited versions of reality, not objective and impartial descriptions of it’(Riessman 1990, p.1197). I came to realise that, epistemologically, I felt most comfortable with a methodology respecting the ‘relativity and multiplicity of truth’(Josselson 2011, p.225) as well as one that required me to reflect on my role as researcher, not only in shaping the way in which my thesis was written, but also in affecting the way in which participants framed their experience within their interview.

3.3.2 Arthur Frank: Dialogical Narrative Analysis

Within the many different approaches to narrative inquiry, I became increasingly interested in the work of Arthur Frank since at the heart of my thesis lie the voices of people living with Parkinson’s and, simply stated, ‘voices tell stories’(Frank 1995, 2013, p.7). For me, the distinctiveness of my participants as storytellers is their illness and, were it not for their diagnosis of Parkinson’s, I would not have spoken to them. Echoing an observation made by Frank, their illness is not just the ‘topic of [their] story; it is the ‘condition of [their] telling that story’ (ibid. p.2).

I have therefore used as my theoretical reference point the work of Arthur Frank, whose Dialogical Narrative Analysis (DNA) approach understands stories as ‘artful representations of lives’ where stories ‘reshape the past and imaginatively project the future’ (Frank 2012, p.33). Narrative truth involves a ‘structured account of experience’ rather than a factual record of what really happened (Josselson 2011, p.225). It recognises that stories may reflect ‘desire for what might have happened’ rather than ‘commitment to an accurate description of what did happen’ and that DNA is more interested in ‘the truth of the telling’ than the ‘telling of the truth’ (Frank 2010, p.90). Thus, my aim in this thesis has been less about garnering ‘facts’

and more about eliciting and understanding ‘narrative tellings’ as a means of articulating the ‘significance and meaning of [...] experiences’ (Bochner 2001, p.153).

DNA is part of a ‘narrative turn’ in the human sciences which challenges ‘a single, monolithic conception of what should constitute scholarly work in favour of a developing pluralism’ (Grant and Zeeman 2012, p.1). It seeks to understand the nature and role of stories and the position of the researcher in relation to the storyteller and the story (Frank 2005, Frank 2010, Frank 2012). It recognises that the ‘second-order representation of these stories in our analyses and interpretations’ (i.e. within this thesis) is, in itself, ‘a process of restorying’ (Mishler 2004, p. 102). Frank also acknowledges the influence of Bakhtin, who stressed the fact that in a dialogical novel ‘the author speaks not about a character but with him’ (Frank 2012, p.34). DNA therefore encourages the researcher to speak with the research participant rather than about him or her.

It is important to note that narrative analysis itself is not guided by a set of ‘formal rules’ (Riessman 1993, 2008), nor is there ‘dogma or orthodoxy... about how to conduct narrative research’ (Josselson 2011, p.228). For Josselson, the aim is to elicit stories around a theme in as unobtrusive a manner as possible, attending to the context of the relationship between interviewer and interviewee, and then to analyse these stories in the framework of the questions that the researcher brings to them, giving due consideration to the linguistic and cultural contexts that shaped the account, both immediate and in terms of the larger culture’ (ibid.).

Whilst the use of narrative as a means of exploring illness is not disputed amongst established researchers, there has been a degree of disagreement over the claims that can be made on the basis of narrative methods and analysis, as well as the significance of narrative inquiry versus other means of exploring people’s illness experience (Thomas 2010). As already stated, I subscribe to the view that any methodological standpoint can only be partial. This study therefore seeks to build on previous studies by using previously unused narrative analysis methods as one of a number of possible approaches to the illness experience of Parkinson’s.

3.4 The researcher journey

Before exploring how I implemented DNA, I shall turn to the ‘inter-related activities’ that I undertook in the design and implementation of this research. It is these activities that have, of course, both shaped and been shaped by my methodological approach. In deciding how best to present them, I have reverted to my original training as an historian, taking refuge in a broadly chronological approach. Please note that although ethics clearance came after I had met with the specialist Parkinson’s Nurse, I did not proceed with any recruitment or clinic and local group observations until I had gained ethics approval for my research. The following timeline highlights the order in which key events took place. These events relate solely to Parkinson’s although, as mentioned above, I also spent considerable time in 2011 establishing links with the MNDA.

2011	Mar	Informal meeting with Sheila
	Apr	Qualitative Research Week
	May	
	Jun	Meet specialist Parkinson’s nurse (SPN)
	Jul	RGEC approval (BSMS)
	Aug	Meet a second specialist PN
	Sep	NRSE Ethics approval received
	Oct	<ul style="list-style-type: none"> • Practice interview (non -Parkinson’s) • Clinic observation
	Nov	<ul style="list-style-type: none"> • 3 interviews • Clinic observation
	Dec	1 interview
2012	Jan	3 interviews
	Feb	<ul style="list-style-type: none"> • 3 interviews • Clinic recruitment • Labtec Conference
	Mar	9 interviews
	Apr	<ul style="list-style-type: none"> • 3 interviews • PUK local group meetings • PUK research update meeting
	May	<ul style="list-style-type: none"> • 11 interviews • Meeting with GP facilitators
	Jun	<ul style="list-style-type: none"> • 2 interviews • Meeting with Neurologist
	Jul	1 interview
	Aug	
	Sep	1 interview
2014	Jun	Meeting with Speech and Language Therapist

Table 1 Research study design: Timeline of key events relating to Parkinson's

3.5 Meetings

Although this is not formally an ethnographic study, I participated in a number of meetings that proved particularly useful for elucidating my understanding of the context in which people are cared for, and also provided routes to recruitment.

3.5.1 Meeting with a specialist Parkinson's nurse

My first meeting with a specialist Parkinson's nurse took place a few weeks after my informal meeting with Sheila. In hindsight, my understanding and interpretation of the meeting with a Parkinson's nurse was greatly aided by having had the opportunity to hear Sheila's story and observe the effects of Parkinson's on her.

Information from the Parkinson's nurse provided me with a valuable means of 'scene setting' prior to completing my ethics application. It was also very helpful when considering issues pertinent to the conduct of interviews. Talking to the Parkinson's nurse helped me gain initial insight into the pathology of the disease as well as the symptomatology and the individual nature of Parkinson's (i.e. the notion that there are myriad associated symptoms and no one person will share the same combination). I also gained some understanding of the role of the specialist Parkinson's nurse and remember my feeling of shock that this nurse had a caseload of more than 500 people with Parkinson's.

The meeting was peppered with snippets of information that I felt compelled to explore in further detail through reading as well as bear in mind during my interviews. These snippets included the nurse's view that 'everything has to be done immediately - Parkinson's patients don't wait' and that many Parkinson's patients display certain characteristics: they might be quite solitary and take up small, detailed, focussed hobbies. The meeting helped raise my awareness of potential sensitivities both in arranging and conducting interviews - not least an awareness that participants may experience 'on' or 'off' days; that there is no standard drug regimen and therefore some people function better in the morning than the afternoon, or vice versa (the nurse referred to this as the 'dynamo versus battery' effect).[°] I was told that 'off' normally means the tablets are failing, and often leads to anxiety which takes an 'organically physical form' and therefore it would be good

[°] The nurse asks patients whether they are morning or afternoon people –i.e. do they wind up to things gradually during the day or are they fully charged at the beginning and then wind down.

to ‘catch people at the peak of their medication.’ This advice helped prepare me for a number of occasions where participants’ medication did, indeed, wear off during the course of the interview (discussed later).

It was also the nurse’s view that it may be difficult to get people to talk without focussed questions; that open-ended questions may ‘prove tricky.’ I actually found this not to be the case with the majority of my participants. The meeting also helped me reflect more concretely on the difficulties of asking people to talk about living with a condition that is incurable, progressive and degenerative – an interview that would inevitably involve people in reflecting not only on their past but also their future: a future where currently there is no cure. In the words of the nurse, ‘talking about treatments of the future may highlight that Parkinson’s disease is a “dead end” illness.’

3.5.2 Clinic observations

In addition to the meeting described above, I observed - over a number of weeks - a number of clinics run by a [different] specialist Parkinson’s nurse. On all occasions the patients attending the clinic had the opportunity to see the nurse without my being there should they so wish, although no one chose this option. I was certainly encouraged by this response, which seemed to echo my other ‘real life’ encounters, as described above.

In clinic, the number of years since diagnosis varied from patient to patient, but I was able to observe an initial consultation (i.e. the patient’s first visit to the Parkinson’s nurse since diagnosis by a neurologist) as well as consultations with people who had built up a relationship with the Parkinson’s nurse over a number of years. It was also helpful to observe relationships – in the context of a medical consultation – between the person with Parkinson’s and their carer.

Through these clinic observations I was able to see the Parkinson’s nurse in action; observe interactions between people with Parkinson’s and a health professional; gain an understanding and feeling for what can be of importance to a person with Parkinson’s when visiting the nurse; learn more about the pathology of the disease and the role of drugs in its treatment; and, above all, observe some of the symptoms of Parkinson’s and how they might affect people.

As I write about these meetings many months after attending them, I still retain strong visual memories of the people I met at the clinics – particularly their arrival and departure. At the end of one consultation, a man with Parkinson’s asked his wife to stretch his arms up for him. Good-naturedly she did this, first one at a time and then both together. She did the same with his legs, unfolding them, stretching them and placing them carefully back. She helped pull him out of his chair and then, as he walked falteringly towards the door, she gave one of his heels a little push with her foot to get things moving. Suddenly, having been virtually unable to move, he sped through the doorway and down the corridor.

Following another consultation where the patient’s mother tongue was not English, I wrote in my notes:

Her husband felt she had been moving better. No freezing while walking. She was quite slow to talk – to me it was not clear whether that was to do with Parkinson’s, with personality, or with language differences. Her husband frequently intervened to finish sentences, but managed to hold himself back on a few occasions. They had been cycling together in X and they laughed about her falling off into a thorn bush. They talked about cooking – there were gales of laughter when [the Parkinson’s nurse] asked if it had improved! She meant, of course, the actual process of cooking. Her husband said he sometimes finishes things off, as it becomes too slow, moving pans etc. around.

I feel quite emotional as I recall these albeit brief encounters and the generosity of so many of the people I met. As this couple left the clinic, she turned to me and said:

“I hope I have been useful for you.”

3.5.3 Local support groups

Having first sought the consent of Parkinson’s UK, and having gained ethics clearance, I attended different support group meetings, which gave me further opportunities to meet people with Parkinson’s and their carers as well as talk about my research study.

One meeting included a talk given by a researcher from a centre of excellence, reporting findings from a study about Assistive Technology for People with

Parkinson's. There was a raffle and, embarrassingly, my ticket number came up. Despite my protestations that someone else should be allocated the prize, I found myself leaving the raffle table with a bottle of wine – cheered on by group members. With a different local group, I spent more than five hours both observing and participating in the meeting, including lunch. A PUK Local Officer talked about plans for a 'trolley dash' at the local hospital, to raise awareness amongst nursing staff of the importance of people with Parkinson's receiving their medication on time when in hospital. After this I was invited to talk about my research, as a consequence of which four people indicated their interest in participating.

The afternoon was especially useful in allowing me the opportunity to hear people express their views on what they - as a group - perceived to be of importance. The three top issues to emerge on this occasion were all talked about in terms of 'lack' – be it quantitative or qualitative. Thus, people expressed frustration at what they perceived as a lack of understanding about Parkinson's by GPs; a lack of understanding in hospital(s) of the need by People with Parkinson's to self-medicate; and very importantly, a lack of specialist nurses (in three neighbouring counties) with those working locally "run off their feet."

Whilst my thesis gives prominence to the stories of my participants as told to me, this opportunity to observe people in clinics and at local group meetings constituted part of the process of 'getting into the field' in order to gain the 'proximate experience' necessary not only for entering into a dialogue with participants' stories (Frank 2012, p.38), but also 'to increase a sense of validity in the interpretation being offered' (Bury 2001, p.282).

3.5.4 Meeting with GPs

6 months after beginning interviews, I met with a group of 9 GPs and talked to them about their experience of Parkinson's within their daily practice. It was a very hot, sultry day and I was grateful not only for the time they gave me, but also the openness with which they addressed my questions, not least given the fact that the meeting took place soon after press reports in which one newspaper article bore the headline: 'Parkinson's: doctors missing early warning signs' and continued with: 'Doctors are failing to diagnose thousands of people with early stage Parkinson's disease because they do not know the early warning signs, a charity warns today'

(Daily Telegraph, 16 April 2012). This prompted one GP to tell the group that she had not recognised Parkinson's in her own father, reminding them that it can 'creep up ... and one doesn't necessarily notice it.' It also prompted brief discussion on the role of non-motor symptoms in Parkinson's and, in line with findings discussed in my literature review,^f a number of GPs were unaware of the degree to which they might affect a person's illness experience.

I was especially interested in i) how the GPs within the group viewed a diagnosis of Parkinson's; ii) how often they would expect to see a patient with Parkinson's; iii) how they kept up-to-date with any development in the management and treatment of the disease and iv) how they viewed their role in supplying information about Parkinson's. My interest in the latter was prompted when attending a local group meeting at which people commented that local GP surgeries were very reluctant to display any information about Parkinson's (published by PUK). As briefly discussed below, there was some variation in response to these issues.

i) One GP referred to Parkinson's as a 'neat diagnosis' since, in his view, 'you know what you're dealing with.' Another said she would not be upset to tell someone if they had Parkinson's as she felt it was not stigmatised. One GP put forward the view that a diagnosis of Parkinson's does not receive much sympathy, as it is not an "exciting" disease. On the other hand, someone felt that someone with Parkinson's would be treated better than someone with a mental illness. When asked where they would place a diagnosis of Parkinson's on a continuum (1-10, with 1 being mild and 10 being serious), discussion resulted in general agreement to place it at just above the halfway point, at 6 or 6 and a half. A number of the GPs expressed the view that age played a role, and that it would be 'ok' to be diagnosed when older, but 'not so good' when younger. Indeed, one doctor suggested that not giving a diagnosis to someone who was older was acceptable. This was countered by another GP who pointed out that this might deprive a person of access to the support services that only become available post diagnosis.

ii) & iii) They thought that the oft quoted statistic of GPs only seeing 1-2 patients with Parkinson's in a year referred to new patients and agreed that there was probably under diagnosis in elderly people. They reported that they mostly kept

^f Todorova et al's paper on the 'neglected' area of non-motor symptoms in Parkinson's (2014).

abreast of new developments (of any type) online or through refresher courses and talks. One GP commented how helpful consultants' letters can be in educating and updating - i.e. if the consultant explains *why* a medicine or dosage is being changed, as well as outlining the expected results. The latter, she explained, is much more helpful and informative than simply being told one medicine is being stopped and another started.

iv) Within this group of GPs, there was an understanding that the Parkinson's nurse specialist dealt with most things related to PD and therefore they did not perceive themselves as necessarily being involved in giving out information regarding Parkinson's. They were surprised to hear that not everyone had access to a specialist nurse and that the local Parkinson's nurse had over 500 people on his books.

3.5.5 Meeting with a neurologist

Soon after meeting the GPs I had the opportunity to meet with a neurologist with a particular interest in Parkinson's disease. The purpose, as with the clinic observations above, was to help in my understanding and analysis of the constituent parts of participants' stories given that each participant's voice is 'resonant with the voices of specific others' (Frank 2012, p.35).

He highlighted the difficulties of making an accurate diagnosis. Some conditions can present with features of Parkinson's disease but are actually the result of different pathological processes. He explained that, statistically, GPs 'get it right around two out of three times' (i.e. in c. 66% of cases). By contrast, he estimated that the accuracy of a Parkinson's diagnosis by Consultants is c.75%, and that of Neurologists c. 80%. Although a diagnosis before the age of 50 is given the name 'Young-Onset Parkinson's' he recognised that 50-55 was 'still young' for such a diagnosis and felt that there 'needs to be better gradation for ages.' He also explained that 'everyone is different' and in his experience 'it is impossible to predict 5 years ahead' in terms of disease progression.

3.5.6 Meeting with a speech therapist

A number of months after I had completed interviews with participants I met with a speech and language therapist (SALT)[§] who ran voice treatment (LSVT)[¶] groups for

[§] The SALT also advises on strategies to overcome problems related to swallowing and choking, which can affect people with Parkinson's.

people with Parkinson's. Many participants had spoken to me about problems with their voice and some noted the irony implicit in a study aimed at 'giving voice' to their illness experience. In particular, some participants spoke of sadness at no longer being able to rely on their voices to express irony or humour, and also spoke of embarrassment at not being able to project their voices as and when required. In addition, the speech therapist had noticed that changes in voice pattern gave the potential for misunderstanding, with people's 'irony' or 'humour' being misconstrued as sarcasm.

Changes to the voice have the potential to affect people's social worlds in a number of ways, and the SALT cited the example of one of her patients who had re-ordered his social relations with reference to the communication styles of others, preferring to socialise with those people who would allow him to speak and finish his own sentences, and only socialise at times when he knew his voice was 'at its best.' She also commented on the role tiredness played, not only in affecting speech but also people's appearance. In her experience, some patients worried that they might *look* depressed and had found that this affected the attitude of others towards them which, in turn, led to some people withdrawing socially. Depression might then become a reality. It was clear that she felt speech therapy should take a holistic, as well as functional, approach to any intervention. Thus, LSVT strategies, although principally aimed at enabling people to speak louder (increase amplitude), also result in beneficial 'knock on effects' through helping people keep track of what they want to say; improving timing generally; and building confidence.

3.6 Recruitment methods

I gained NRES approval for a variety of recruitment methods, all of which I used (please see Figure 4 below). As already intimated, recruitment - and interviews - took place in parallel with the activities mentioned above.

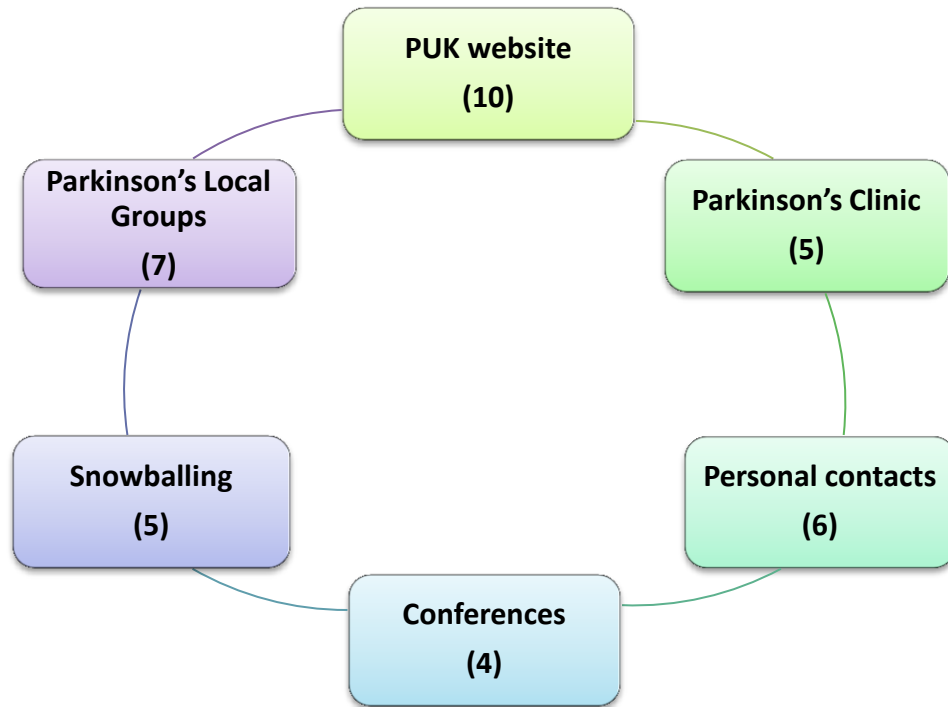


Figure 4 Recruitment routes. Total: 37 participants

3.6.1 Parkinson's UK Website

Through the larger LABTEC project I was able to make contact with colleagues at Parkinson's UK and, following her attendance at a LABTEC conference,^h the Research Liaison Manager not only agreed to advertise the study through the PUK website but also communicated directly with Local Group Officers, asking them proactively to spread the word through newsletter and local group meetings.ⁱ I was contacted by a number of people through this route, ten of whom I later interviewed. It was using the Parkinson's UK website with its national audience that led to my travelling more widely, resulting in my interviewing people from 8 different counties.

3.6.2 Parkinson's clinics

As outlined above, I observed a number of clinics. One of the specialist Parkinson's nurses suggested that I use the clinic as a means of recruiting participants. Thus, on one occasion, rather than observing clinic, I sat in the waiting room. While the

^h The conference, held at BSMS in February 2012, was entitled "Neurodegenerative disease, biography and identity."

ⁱ Please see Appendix 2 for a copy of the PUK advertisement.

secretary kindly handed out flyers^j to patients attending the clinic, I sat as discreetly as possible, available for people to ask any questions should they wish further information or wish to take part. I had put my photograph on the flyer and people were therefore able to identify me as the person to whom they should address questions. Five people participated in this study as a consequence.

3.6.3 Local Parkinson's groups and conferences

Approval from Parkinson's UK at national level enabled me formally to establish links with Local Parkinson's UK groups and seven people asked to be involved in my research through this route. I also attended conferences and talks related to Parkinson's and, with permission, distributed flyers about my research. This resulted in four people participating in this study.

3.6.4 Personal contacts and 'snowballing'

Through personal contacts, a further six people agreed to be interviewed. For me, this was perhaps the most surprising route. As mentioned at the outset of this chapter, I started this research with no substantial personal knowledge of Parkinson's. And yet, as I spoke to friends and acquaintances about the new direction in my life, I discovered that a surprising number of them knew someone affected by Parkinson's – ranging from a close relative to a friend of the family. Not only did six people come forward for interview as a result of these unforeseen connections, but a further five participants came forward as a consequence of a "snowballing" effect – i.e. having heard others talk about their participation, they contacted me and asked to participate themselves.

3.7 Interviewing

Just as there is a burgeoning literature on qualitative research, so too there is a growing literature addressing methodological and ethical issues associated with 'the interview' (Kvale 1996, Kvale 2006, Kvale and Brinkmann 2009, Rubin and Rubin 2012). Kvale's position appears to have moved over the years through viewing the interview as "a conversation between two partners about a theme of mutual interest [...] a specific form of human interaction in which knowledge evolves through a dialogue" (1996, p.125) to a rather more trenchant view ten years later, in which he appears to disagree with his former self:

^j See Appendix 4 for an example.

‘Referring to the interview as dialogue is misleading, although a common practice.... giv[ing] an illusion of mutual interests in a conversation, which in actuality takes place for the purpose of just the one part – the interviewer’ (2006, p.483).

In conducting my research I have certainly tried to remain alert to the asymmetrical power relations at play. In quite critical terms, Kvale states that the researcher ‘determines the time, initiates the interview, decides the topic, poses the questions and critically follows up on the answers and also closes the conversation’ (ibid. p.484). Of course, at one level much of this is true, but it is nevertheless important to remember that participation in this study was wholly voluntary. Indeed, many participants initiated contact with me rather than the other way round, suggesting that my research might fulfil some need for them. There actually came a point – as anticipated by the Ethics Committee - when I had to explain to people enquiring about participation that, sadly, I did not require any further interviews for the purposes of this particular study. The relative ease in recruiting for this project suggests that its aims, and the manner in which it was communicated to people via my Participant Information Sheet,^k appealed to many people with Parkinson’s. It appears to suggest that, from the outset there were people with Parkinson’s who wanted the opportunity to tell their story, and this concurs with the view of healthtalkonline researchers, discussed in my literature review, that people with Parkinson’s are sometimes ‘desperate’ for others to understand what life is like for them.

I undertook 37 face-to face interviews between November 2011 and September 2012. I was keen that the study should be inclusive as possible and participants were reasonably well balanced in terms of gender and their age at diagnosis. The latter spanned 6 decades, ranging from 29 to 78, and the length of time since diagnosis also varied considerably, with the most recent being 3 months, and the longest being 33 years. Participants came from eight counties within England, but I have not made reference to the county of origin (table below) for reasons of anonymity. Whilst there is some variation in the socio-economic class of participants, there was a lack of ethnic diversity. This may, in part, reflect the local

^k Appendix 3

demographic, particularly amongst the older generation, but it is also interesting that a wider call through the PUK website did not attract any participants from a black and minority ethnic (BME) group. According to academic studies, the incidence of Parkinson's within BME groups remains uncertain and has been 'a source of controversy for many decades' (Van Den Eeden, Tanner et al. 2003). However, Parkinson's has been 'found in all the ethnic populations studied' although some studies have suggested that it 'less common in the black community' (Chaudhuri, Clough et al. 2011).

3.7.1 Participants

Female	Age	Years since diagnosis	Occupation at diagnosis	Occupational status at interview	Male	Age	Years since diagnosis	Occupation at diagnosis	Occupational status at interview
Zoe *	36	6	Marketing	Self - employed PD	Keith*	47	17y 9m	Manual labourer	Unemployed PD
Sheila*	53	8y 7m	Shop Assistant	Unemployed PD	Charles	82	4y 9m	Retired	Retired
Jean	66	3m	Carer	Carer	Ted	72	c 4y	Health professional	Retired
Edna	77	33y	Bank Clerk	Retired at 60	Adam	69	5y 8m	Surveyor	Retired
Pat	72	2y 6m	Retired	Retired	Henry	67	c 15y	Management	Retired PD
Joyce	72	2y 8m	Retired	Retired	Richard	60	7m	Editor	Retired PD
Mary*	52	7y 10m	Engineer	Sick Leave PD	Lee*	54	18y 6m	Jeweller	Retired PD
Barbara	72	1y 6m	Retired	Retired	Jay	59	6y	Engineer	Desk job PD
Angela	69	11m	Retired	Retired	Philip	59	5y 2m	Farmer	Retired PD
Sarah*	55	13y 6m	PA	Unemployed PD	Derek	71	6-7y	Engineer	Retired PD
Janie	63	10y	Counsellor	Unemployed PD	Jonathan	72	4y 10m	P/T Market Researcher	Retired PD
Marianne*	50	8y	Airline industry	Unemployed PD	Neil	67	4y	Doctor	Retired PD
Joan	55	3y	Teacher	Unemployed PD	Colin	74	11y	P/T Journalist	P/T Desk Job PD
Kay*	51	2y	Health & Care professional	Part time PD	Julian*	54	5y 5m	Scientist	Charity worker PD
Caitlin*	57	9y 10m	Charity Worker	Unemployed PD	Rory*	48	1y 11m	Financial sector	Financial sector
Janet*	51	5y 3m	Cleaner	Unemployed PD	Adrian	73	17y	Engineer	Retired PD
					Michael*	65	19y	Surveyor	Early retirement PD
					Oliver*	40	4y	Academic	Unemployed PD
					Darren*	47	1y	Civil Servant	In limbo PD
					Bill	78	4y 6m	Insurance	Retired
					Norman	66	6 y	Engineer	Retired

Table 2 Participants by gender, age, length of time since diagnosis and occupational status

In the table above, an asterisk* indicates a diagnosis of Young Onset Parkinson's (i.e. participants were diagnosed at or under the age of 50). I have included two columns relating to occupation: occupation at the time of diagnosis and occupational status at the time of the interview. PD under occupational status indicates that participants attributed any change in status to their diagnosis of Parkinson's.

3.7.2 Practical arrangements

I put considerable time and effort into arranging the interviews to suit my participants. Many had chosen to use e-mail as a means of corresponding, but I made arrangements by phone in some instances. Communication was doubtless eased by the fact that I had already met a number of participants - either at clinic, conferences or local group meetings - or people felt a degree of ease because their relatives or friends knew me. I remained as flexible as possible over when and where we should meet (subject, occasionally, to travelling times) - and the vast majority of interviews were conducted in participants' homes (the place they wanted to be) at the time of day suggested by them. In two instances I managed to arrange two interviews on the same day, when I needed to travel a considerable distance to get there. As somebody who reverts to wearing black in the autumn and winter, I gave considerable thought to the clothes I wore, especially their colour, aiming for something a little more neutral.

On arrival, it was important to make sure that participants felt comfortable about talking to me, and I took time to ensure that they were happy with all information in the Participant Information Sheet; that they had time to ask me any questions - including questions about me should they wish to know more; that they saw - and were happy about - the voice recorder before completing the consent form; and, above all, that they knew that they may pause, take a break, or simply stop the interview at any stage. Before the interview proper, I asked if people were happy to give me their date of birth and date of diagnosis (nobody objected to this) and always asked permission to make a few notes by hand in case I needed a written reminder of points that may need expansion or clarification later in the interview.

Meeting people in their own environment meant that I was on their territory; they were host, introducing me to anyone else who may be in the house, offering me a drink, deciding where we should sit. I believe that this was helpful for allaying any

anxiety they may have about the interview process. Interviewing people at home also allowed me a fascinating glimpse into their personal world, free from the pressures of the work place or clinic. Seeing photos, pictures, ornaments, books, DVDs, furniture (even the same curtains as my own) offered me important visual clues to their identity and opened up opportunities for stories that would otherwise have remained untold, especially before and after the interview. I always took a small gift as a thank you -usually a plant - and was touched by how pleased many participants were by this small token. One participant even e-mailed me pictures of the plant I had given him, hoping that I would enjoy seeing it in full bloom.

Even though I was party to observing and being told about many limiting factors within the home, the constraints imposed on people by Parkinson's became more apparent on the occasions I did meet someone outside their home. The degree of planning required for interviews to take place away from the home environment, and my own need to adjust to accommodate a different range of disabilities, highlighted the loss of spontaneity experienced by so many people with Parkinson's. For one participant, taking public transport was impossible. Although she was happy for me to pick her up and interview her at the university, it was important to ensure I reserve a parking space as well as gain access to the key for the lift. Two other participants whom I interviewed at the university found arriving at the appointed time very difficult, due to difficulties with waking, being "switched on" by their tablets, and getting themselves ready. Meeting one participant in a pub garden allowed me the opportunity to observe others observing him. He suffered from considerable dyskinesia and it was immediately apparent that extending the normal courtesies to me, such as buying and bringing over a drink, were extremely difficult for him, as well as provoking comment from other people in the pub. However, the effort to which many participants went in order to be involved in the study highlighted what appears to be a human need to remain productive and, as well, the role of reciprocity within such exchanges.

3.7.3 Guided conversation

The interview itself took the form of a 'guided conversation' as opposed to a series of set questions determined by pre-set themes. I took this term from Professor Clare Williams et al's ethnographic study of medical staff's perceptions when working with embryos.⁷ This approach concurs with Mishler's reconceptualization of the

research interview as a ‘discursive accomplishment’ in which two active participants ‘jointly construct narrative and meaning’ and a detailed account is generated (Riessman 2008, p.23). For Mishler, the ‘standard approach’ obscures the role of discourse, reducing the research interview to a matter of technicality in which the interviewer elicits information from another person. He therefore proposed a ‘new definition’ centring on a view of the interview ‘as a discourse between speakers and on the ways that the meanings of questions and responses are contextually grounded and jointly constructed by interviewer and respondent’ (1986, pp. 167-8). This idea has been further developed by Kvale, for whom the interview is a ‘stage upon which knowledge is constructed’ (Kvale 1996, p.127) where participants should feel free and safe to talk of ‘private events for later public use’ (Kvale and Brinkmann 2009). In my own interviews I aimed to strike a delicate balance between pursuing knowledge for my study while nevertheless respecting the integrity of my interviewee.

In preparation, I conducted a pilot interview with someone diagnosed with a progressive neurological disorder (not Parkinson’s) who commented that it was ‘well thought through and allowed me to express things in a comfortable, open manner.’ I subsequently tried to ensure that all my interviews allowed participants to feel similarly.

I aimed to give the participant the opportunity to talk about their diagnosis of Parkinson’s and what had been important to them up to and including the stage of the condition that they had reached. I did not have a fixed set of questions, but rather asked people if they were happy to begin by telling me what it was that led them to suspect that something was not quite right, leading up to diagnosis, and then talk about their life since diagnosis. All participants were aware, through the Participant Information Sheet, of my interest in their attitude towards medical research, and therefore most commented upon it of their own accord at some stage during the course of the interview. In a few instances I was the one to initiate reflection on any views they may hold, usually because it seemed relevant to something they had just mentioned.

Whilst remaining cognisant of the view that ‘the purpose of the interview is not to offer any sort of therapeutic intervention’ (Lowes and Gill 2006), it became clear

that, for some participants, the interview offered a form of ‘serendipitous therapy’⁸ - the means by which they could ‘unburden their feelings to an interested listener’ which ‘may be construed as helpful or healing in some instances’ (Kvale 1996). Indeed, it has been proposed that it is these positive ‘side effects’ - the opportunity to give voice to their own experience, to make the unconscious conscious; the opportunity to reflect and be in the presence of an attentive listener - that may help explain why qualitative researchers find participants pleased, often eager, to talk about very difficult, personal or emotional topics (Colbourne and Sque 2005).

To illustrate how this worked in practice, I turn now to a moment in Pat’s interview. Even now, looking at her transcript again, it is remarkable for its density. The first three pages (there are 23 altogether) show only my opening invitation to tell me about her experience and then only four very brief comments which either serve to check what she has just described (e.g. I say ‘dyskinesia’ and a couple of minutes later, ‘deep brain stimulation’) or ask for clarification (‘Is it?’ and then ‘In what way?’). It was an interview where she rarely paused for breath but where emotions also bubbled to the surface. She became quite tearful as she reflected, now in her seventies, on her role as the head of her family and the realisation that ‘I’ve done something right... they’ve all turned out to be nice people.’ After talking almost non-stop for 52 minutes, she said, quite out of the blue, ‘this is doing me good, because I haven’t spoken to anybody about this at all. This is rather good, this is, yes....’ It seemed a genuine moment of epiphany for her.

I remained as alert as possible to any indication that a participant may wish the interview to end and I found that this was, for the most part, guided by participants themselves, usually due to tiredness, or feeling that they had said enough for the time being or that they needed to be somewhere else. As a consequence, interviews lasted on average an hour to an hour and a half, providing an ‘undiluted focus on the individual’ (Ritchie and Lewis 2008). It also seemed to fit well with people’s tiredness levels and the effect on their voice of talking at length. For Sheila, tiredness affected her ability to think, and just after an hour she said, ‘I’m thinking, I’m thinking quite hard, I’m aware that my mind is not concentrated as much as it was now, it’s sort of not able to hold the thread somehow.’ For Janie, the tiredness also affected her voice:

J: Right. Talking of which, Janie, you've been talking for quite a long time.
Janie: I can rabbit when I need to.
J: No, no, not rabbiting at all. One hour, thirty seconds.
Janie: Really?
J: How are you feeling?
Janie: A bit tired.
J: Yes
Janie: I feel my words are sort of blum, blum... I never thought I'd get tired.

I also found that the more interviews I undertook, the more aware I became of a 'saturation' point – partly influenced by a greater understanding of what constituted an illness story and partly influenced by my knowledge of just how long it took to transcribe an interview. Invariably though, participants ended the interview by kindly suggesting that should I need any clarification on anything, or further information, I should simply e-mail them in the future. I did not actually find it necessary to do so.

3.8 Researcher experience

I am cognisant of the differing views held by qualitative researchers about who should transcribe interviews – i.e. the interviewer or a professional transcriber. Transcribing offers a truly effective way of becoming familiar with one's transcripts but it is a very time-consuming task,' taking 'several times the time it took to make the recording' (Robson 2011, p.478). Although I opted to use a professional transcriber for the majority of my transcripts, I decided to transcribe my early interviews as well as some later ones that posed specific challenges, such as one in which the participant had severe speech impairment as a consequence of Deep Brain Stimulation (DBS). Throughout that interview I was able to make occasional notes that would help me during the transcription process. Nevertheless, there were occasions during the interview where I took the decision not to ask the participant to repeat himself, as this, I felt, drew unnecessary attention to his communication difficulties. As a consequence, there are parts of the interview that remain difficult to understand.

Overall, I transcribed 10 of my interviews, both to become familiar with my data, and to reflect on my interview style. Transcribing also allowed me to insert comments related to aspects of the interview such as: body language and emotions (e.g. what triggered an emotional response in the participant, such as sadness, anger, and tears? What questions or subjects motivated or energised people? What made

people reflective?). I also made a note of my own emotions and feelings during the interview. I then repeated the process for the transcripts that had been professionally transcribed, at the same time checking for accuracy of transcription.

Some researchers return transcripts to participants for ‘correction and approval’ before analysis (Frank 2005, p.965), but to have done so for this study would have been to contradict my methodological approach. As discussed above, at the core of DNA lies the concept of ‘unfinalisability,’ recognising that people constantly tell and retell stories. It has been imperative that, in my role as researcher, interpreter and analyst, I have not sought to understand any of my participants as being ‘fixed’ in any representation of their words (ibid. p.967). Rather, my interest has been to hear how participants told their story on a particular day, in a particular environment. To have returned transcripts might have been to invite participants to ‘revise’ their story which, in itself, might have suggested that there is a ‘right’ or ‘final’ version to be told whereas each story, when told, is arguably ‘no more or less true to [a person’s] experience than [the] old one’ (1995, p.23).

3.8.1 Field Notes (reflexive journal)

Following each interview, I wrote field notes reflecting on the experience – notes which have informed some of my analysis and parts of which I have used to ‘set the scene’ at the beginning of each transcript. These notes - in the form of a self-reflexive diary - were not only part of the process of self-care, but also a means of trying to capture and record the experiential aspects of conducting interviews. They have helped form a platform from which I can assess feedback or any extended contact with participants. Above all, they have been important when re-reading the transcripts, both as a means of transporting myself back to the moment I met people, and as an aid to understanding my role as a researcher.

3.8.2 ‘Setting the scene’

This ‘setting the scene’ chimes well with Jorgen Jeppesen’s use of observational data in his narrative analysis of interviews of people with Motor Neurone Disease (MND) (Jeppesen and Hansen 2011). During the LABTEC conference at which he was a key speaker, Jeppesen talked of the importance of observing what he referred to as ‘trivia’ during an interview, and the concomitant importance of conveying aspects of this observed ‘trivia’ in the re-telling of someone’s story. Although

people are struggling with very difficult illnesses, the acknowledgment of small details - the bright red of a rose against the green of the grass - is also an acknowledgement that 'life goes on.'

Again, to illustrate what this means in practice, I shall turn briefly to a particularly poignant interview I undertook with Edna, who was severely affected by Parkinson's, having been diagnosed 33 years before. Trapped in her house and chair, the view of her garden through a French window was of paramount importance to her and her well-being. She had spoken of her enjoyment at watching the birds...

'I spend a lot of time watching the birds. Not really this morning, but you do really. Some days there are lots of them about, some days there are a few and squirrels and even the odd fox. Robins...pigeons (it was difficult for her to get this word out)...and the squirrels there. I like to see them because they...stand up and...that bird tray's...only a very fine one, it's supposed to be for little birds but the pigeons walk round the bottom while the birds are on top and they seem to find more on the floor than got in the pot. And it's quite fascinating to watch them sometimes.'

A few minutes after she had told me this - with great effort on her part - a robin landed on the bird table. She nodded at it, and although we had moved on to a different topic it seemed comfortable to stop and watch the robin. We did so for nearly 5 minutes.

3.8.3 Role reversal

It is certainly interesting to reflect on Kvale's point that the conversation in a research interview is 'not the reciprocal interaction of two equal partners' (1996, p.126), given that the researcher 'defines and controls the situation' (p.3). To this end, he illustrates how the implicit rules become visible only when they are broken, for instance through 'role reversal,' when the interviewee asks the interviewer a question and the latter is quite taken aback (p.125). On re-reading my field notes, it is perhaps a little surprising to me that it was not until the 10th interview that this 'role reversal' happened - albeit not in the actual interview. In my notes I recorded the following:

I travelled to X by train. On arrival at the house there, indeed, was the green sports car in the drive, as Richard had said there would be (he told me later that it had been a mid-life crisis purchase by his wife). There was a glass front door behind which was a small porch. There was no bell or knocker, and I felt too timid to open that door and was unable to see (such is my eyesight!) that there was a bell on the inner door. So I phoned Richard – and he answered, and came to the door still on the phone. He looked barely older than me, but walked slowly with an ever so slightly stooped gait. He offered me a coffee and, as he made it, told me that caffeine and smoking are both meant to be neuro-protectors. He is happy to carry on with the caffeine intake – any excuse for a coffee – but having given up smoking, said his wife would kill him if he took it up again. There was something instantly likeable about him, and he seemed genuinely pleased with the small (spring!) plant I had taken. We sat down - he in an armchair, me on a sofa diagonally opposite - and he asked me to tell him about myself! He is the first person to have done that, and I felt it was only fair to respond. After all, he had not met me before and knew nothing about me but for the information in my flyer and the Participant Information Sheet. I tried not to speak for too long and only talk about myself as long as it seemed both interesting to him and relevant, if that makes sense. I felt it was only reasonable that, just as I was about to try and understand life for him, and ask him to tell me things about himself that are probably quite personal, so, too, should he know a little bit about the person to whom he was about to open up.

3.8.4 Intriguing encounters, challenging situations

In trying to accommodate people's needs, there were - perhaps inevitably - some intriguing encounters, including an interview at a private member's club; one in a noisy pub garden; one in an 8th floor boardroom and another where, on arrival at the participant's house, the scaffolding on the outside was, indeed, a clue as to the inside, and with neither a chair nor a square foot of floor in sight, we took to the drizzly, wet streets to find a suitable place for an interview.

Similarly there have been challenging situations during interviews - other than purely environmental - on which I shall reflect during the writing of this thesis. They include participants suffering from dyskinesia (involuntary movements); considerable speech impairment (in two cases as a consequence of Deep Brain

Stimulation) or, alternatively, very rapid, almost unintelligible, speech; freezing; and becoming very emotional. One participant spent considerable time deciding whether or not to lie on the floor for the interview. I admit to a feeling of relief when she opted for her chair. Some of these challenges inevitably affected transcription, as already indicated.

3.8.5 Confidentiality, anonymity and any issues arising after the interview

As outlined above, having gone through the Participant Information Sheet with participants (sent out in advance) and answered any questions, all participants signed a consent form.¹ They were all in agreement that I choose pseudonyms on their behalf and were happy for me to use a voice recorder during the interview. I sought permission to contact them a couple of days after the interview (in order to reiterate my thanks) and check whether any interview-related issues had arisen. I also informed all participants of people whom they might contact should the interviews raise any unanticipated issues that they may then like to talk through. I anonymised transcripts (with pseudonyms) from the outset. Transcripts and audio recordings have been stored securely. As agreed by the NRES Ethics Committee, data will continue to be stored securely for 10 years according to university policy.

Confidentiality and more particularly anonymity emerged as a major ethical and methodological concern that was discussed frequently with my supervisory team. I had to acknowledge that choosing to present such rich versions of some participants' stories in my final data chapter meant that the possibility of anonymity was less real despite my best efforts to combine authenticity with protected identity.

3.9 Second meeting

As mentioned previously, a study such as this does not simply proceed in a linear manner. I used my early interviews as a means further to reflect on my choice of methodology, noting how early interviews may challenge or endorse my methodological approach. To illustrate how this worked in action, I wish to introduce Charles, my third participant.

¹ Appendix 5. One participant was unable to write and her husband signed on her behalf, in her presence with her agreement

The interview with Charles, who had been diagnosed for four years, took place at my house between Christmas and New Year. He had been visiting his son, daughter-in-law and grandchildren for Christmas. Just before the interview, my two sons went out with their father and a wonderful stillness descended on the house. Charles arrived and he was clearly delighted to have left the noise of his Christmas behind him, put down his walking stick and sink into the sofa. With the fire burning quietly and the Christmas tree lights glowing softly in the background, we sipped from mugs of tea. It was only once he had gone that I realised how tiny those sips must have been, for despite picking the mug up and drinking from it on a number of occasions, there was still a considerable amount of tea remaining at the end of nearly two hours.

I had been spellbound for much of the interview, and also very moved. As it came to an end, I thanked Charles for giving up his time, to which he replied, 'I haven't given up my time at all – I have chosen to use it in this way.'

I then added that I hoped reflecting on his experience of living with Parkinson's had not caused him any distress, to which he answered without hesitation: 'No, no... No distress. I've enjoyed it very much. No, I think ... a lot of things I believe, I don't actually know I believe until I've said them – heard myself saying them, you know, so that's what I value about talking like this. It's a marvellous opportunity.'

By the time I met Charles I had already read some of Arthur Frank's work and, as already discussed, had become increasingly interested in his conceptualisation of dialogical narrative inquiry (or analysis) as an approach to illness stories (Frank 1997a, 2004, 2005, 2010, 2012). The momentary reflection from Charles at the end of our meeting therefore sang out to me, affirming Frank's views that, in terms that are dialogical, 'authenticity of self' is created in the process of storytelling. Quoting Bakhtin, Frank explains that:

'Stories, as dialogue, do not present a self [ready] formed before the story is told. Rather, in stories the person "becomes for the first time that which [she or] he is—and we repeat, not only for others but for himself [or herself] as well." Narrative analysis can show how that process of becoming "for the first time" works, even as the analysis itself is another stage in this on-going process (Frank 2002, p.115).

I do not wish to overstate any meaning inherent in Charles' remark, but I nevertheless wish to acknowledge the part it has played in endorsing some of the methodological decisions I have taken. These decisions have, in turn, guided the methods used in this thesis. Of course, decisions have not been taken on the basis of this one remark, but rather I have come to understand my ontological and epistemological viewpoints over a period of months, during which time I have been caught up in a symbiotic process of reading, listening, discussing, interviewing, reflecting and writing.

3.9.1 In the flesh: the importance of face to face meetings

As previously reported, I managed to meet all participants in person and therefore all interviews were conducted face to face. Prior to my interview with Charles there was a suggestion that, should we not be able to meet in person, I might conduct the interview with him over the internet. Instinctively I knew that such an approach was not one I wished to take, but I also knew that instinct was not sufficient grounds for declining his kind offer of participation in my research. Fortunately, we were able to meet in person and, returning to my field notes, I see that it was after meeting Charles that I made the decision that I would only conduct face-to-face interviews within this piece of research. But I now had more than instinct on which to rely. I wrote:

Just before the interview began Charles told me that he suffered from narcolepsy. I asked him what I should do were this to happen during our conversation and he told me not to leave him but rather wake him up. Happily, he stayed awake throughout! Nevertheless, there were occasional long silences during the interview, in which I sensed he needed a break, both to gather his thoughts as well as to reflect on what he had just said and what the views he was expressing actually meant to and for him. The importance of being present at the interview - as opposed to conducting it over the phone or internet - and able to read body language, not be afraid to wait and not immediately try and fill the silence - was truly highlighted for me. Listening back to the interview, the pauses feel almost painful - and yet at the time they felt perfectly natural.

3.10 Other voices

This study has been designed specifically to hear the voices of people with Parkinson's, but there have been a number of instances where the partner (carer) has returned home and my participant has invited them to take part. This has posed a methodological challenge in as much as the addition of another voice not only alters the dynamics of the interview but has also required me to question whether the story I then heard was about the couple or the individual. It has, though, underlined the degree to which some participants have wanted to engage in my research, acknowledging that the voice of the person involved in their care is also very important in understanding the experience of living with Parkinson's. On the other hand, one participant who was clear that the interview should not involve anyone but the two of us, conducted parts of our interview in hushed tones rather than closing a door.

3.11 Unsolicited feedback

Within my research design I did not ask for formal feedback about the interviews I undertook, but many people did comment, usually just after I switched off the voice recorder. In line with the findings of other researchers, feedback I received suggests that the interview, rather than being the cause of distress, acted as a means of 'expressing' distress (Lowes and Gill 2006). Nobody spoke of regret at participating, and comments ranged from 'I have enjoyed it. I think it's been good for me' to someone realising 'It's helped me untangle things.' For another the process was 'cleansing' and she realised that it was 'rare to have someone sit and listen.' Such feedback was helpful for reflecting on and trying to understand my researcher role as perceived by participants.

Feedback not only came in the form of words, and it is striking that several participants have wanted to do something beyond the interview, offering me added insight into their lives and identities. One participant sent me complimentary tickets for my family to attend a local stadium event. Another, whose interview had ended with a discussion of train game apps that my son might enjoy, later e-mailed me pictures of his garden railway to show my son. Another, on discovering my son's love of trains, was very keen for me to relieve him of some Hornby engines, carriages and track. I later learned from his wife that he spent days preparing them

for me. I also received two beautiful cards painted by another participant – now framed and hanging on my study wall. I think of her every day as I enter my study to continue writing.

3.12 Analysis: ‘its own singular way’

3.12.1 Frank’s five commitments

Frank points to the fact that ‘every narrative analysis needs to discover its own singular way to proceed’ (2010, p.112), arguing that DNA is less a method and more a ‘practice of criticism’ that involves analytic and interpretive ‘movement of thought’ (p.73).

As previously mentioned, there are no prescribed steps for undertaking narrative analysis. Nevertheless, Frank proposes five methodological *commitments* that are crucial to conducting *Dialogical Narrative Analysis* (Frank 2012). Briefly, they comprise: a commitment to recognising that ‘any individual voice is actually a dialogue between voices’ (ibid. p.34). Indeed any one voice is comprised of multiple voices and the method is interested in hearing how multiple voices are represented in the voice of the interviewee. Thus, for Frank, ‘in any one person’s speech multiple communities intersect’ (ibid. p.35).

A second commitment is to resist social science’s tendency towards monologic interpretations that aim towards distilling some form of ‘truth.’ As noted by Mowrer over eighty years ago, ‘facts are not born full bloom to be plucked by anyone. In every perceptive experience there is an infinite number of observations which might be made but which are not. What the individual sees is determined in part, at least, by what he [sic] is trained to observe’ (1932).^m Instead, Frank wishes to bear witness and gather voices to allow the voices to hear one another and to be heard collectively (ibid. p.36).

Frank defines the third commitment of DNA as recognition that stories have ‘provisionally independent lives’ and are thereby both subjective and external at the same time. Hence, ‘when given close consideration no story is ever anyone’s own but it is always borrowed in parts’ (ibid. p.36).

^m Taken from Gilgun (2005 p.258).

Most important for Frank is the fourth commitment, which comes directly from Bakhtin's concept of 'unfinalisability.' By this account stories have no ending because people constantly retell them in order to develop and revise their understanding of self. This seems particularly suited to a study of Parkinson's, where the trajectory of the disease is uncertain but change is inevitable and people may be constantly 'forced' to re-evaluate their identity.

Underlying any interpretive response is an understanding that interviews may finish, but participants' stories continue. As researcher, I have gained only a snapshot of people's lives and what they chose to disclose to me on the day - at that particular time, in that particular place. This creates an important and interesting tension not only for me but for any qualitative researcher, since 'research reports have a practical need to end' (Frank 2012, p.37). Arguing that the researcher has a tendency to seek constancy, Frank is keen to stress that what remains the same is not the storyteller but rather their recognizable range of narrative resources. Herein lies the possibility for drawing conclusions and ending a report – or thesis.

The final commitment of the DNA approach is that it does not seek to summarise findings – a word that implies 'ending the conversation' and taking a position apart from and above it. Rather, it seeks to enhance and maximise the possibility of participants hearing themselves and others and open the way for further listening and responding (ibid. p.37).

In establishing my own 'singular way,' I wish to acknowledge a debt not only to ideas drawn from the literature, but also to ideas and suggestions emerging from productive discussions with my supervisors. I also took heart from Arthur Frank's reflections on the interpretive process i.e. that interpretation proceeds *slowly* and that narrative analysis requires the researcher to 'slow down' and take exercise when the work of interpreting becomes 'stuck' (2010, p.108). I discovered that continuing with my preferred exercise often – unexpectedly - produced new thoughts, pushing me forwards at points where my ability to analyse and interpret seemed to have become 'stuck.' Frank's words helped assuage the anxiety and guilt I experienced during the times when I could no longer sit at my desk and write.

3.12.2 Managing multiple stories

My work as the person interviewing people with Parkinson's, transcribing their stories and reading and re-reading my transcripts, has been to hear multiple stories about similar events or experiences and then connect these stories (Frank 2010, p.102). Meaning is not inherent in an experience and therefore it has been important to establish the themes that unify the stories of living with a diagnosis of Parkinson's in the 21st century, as well as highlight any disparate voices that 'carry, comment on and disrupt the main themes' (Josselson 2011, p.226). I have borne in mind the relational, social and historical context of any stories of Parkinson's that I have elicited (ibid.) recognising that my work with people's stories is an 'interpretive enterprise' involving 'the joint subjectivities of researcher and participants' (ibid. p. 225).

In working with my participants and their stories, it has been important, as researcher, to gain 'sufficient proximate experience' of the everyday circumstances in which people learn and tell their stories, whilst at the same time understanding and reflecting on the strengths and limitations of my role as researcher (Frank 2012, p.38). In addition, I have tried not to begin with any preconceptions of what ought to change since that would 'foreclose dialogue' (ibid. p.38).

Finally, I have had to be very clear about whose voices are heard. I have had the privilege of hearing 37 different accounts of living with Parkinson's. All these accounts have proved 'appropriate material' for dialogical narrative analysis (Frank 2010, p.21) which, as a minimum, requires that 'a central character encounters a problem, struggles with it and, in the end overcomes or is defeated by it or is changed in some way.'⁹ However, the permitted length of this thesis does not allow me to represent, in whole, all 37 voices and therefore, although each story should be *considered* as a whole, selection has been key to the production of my thesis.

3.12.3 Phronesis

'Which stories to select is crucial' (Frank 2012, p.43) and in accordance with this suggestion I have selected stories for focused attention on the basis of phronesis – the 'practical wisdom gained through analytic experience' (ibid.).ⁿ Phronesis

ⁿ For Aristotle, phronesis 'deals with the ultimate particular thing, which cannot be apprehended by Scientific Knowledge, but only by perception' (cited in Kvale and Brinkmann, 2009, p.67).

involves cultivating one's perception and judgement in order to see and describe events within any given context (Kvale and Brinkmann 2009, p.67). There are always alternative courses of action, and therefore phronesis demands that researchers exert judgement, not only in weighing alternatives, but also in determining which facts might be relevant and, equally importantly, determining 'the choice of responses to those facts' (Haimes and Williams 2007, p.465). In practice, this has meant cultivating the capacity to 'hear' which stories I should write about, whilst nevertheless remaining true to the above five commitments. There is, of course, no escaping the fact that this thesis is *my* representation of participants' stories, given that research, stripped bare, is 'one person's representation of another' (Frank 2005, p.966). As such, I take full responsibility for the decisions I have made over whose voices to bring into the foreground – or assign to the background - at any one point. It has been an absorbing process, filled with surprises – not least the feeling, at times, that the stories represented within these pages have 'chosen me,' perhaps due to my judgement resting in part on 'tacit' knowledge accumulated during fieldwork (2012, p.43).

3.12.4 Opening up analysis

Any narrative analysis requires 'multiple readings' (and, in my case, 'listening to') of each interview (Josselson 2011, p.228) and to open up analysis and start the process of familiarising myself with my transcripts I wrote a number of 'vignettes,'^o based on both the interview and my field note observations. Through this process I aimed to capture the context and overall feeling of interviews, taking into account how participants presented themselves on that particular day, as well as my role as interviewer.^p It proved a valuable starting point for gaining a sense of the narrative structure of an interview and attuning myself to general themes emerging from individual stories (ibid.). In addition, vignettes highlighted some of the kinds of story at play within people's narrative accounts, including stories of loss; stories of isolation; stories of hope and reinvention; stories of comparative suffering; stories of the mastery of illness and stories of adjustment.

^o See Appendix 6 for an example of a vignette.

^p See Appendix 7 for a journal entry that tried to capture a general sense of the vividness of interviews.

3.12.5 Navigating the transcripts: ‘The Capacities of Stories’

During the iterative readings (and ‘listening to’) of my transcripts that followed the initial reading, I produced a ‘cover sheet analysis’ for each participant. I read transcripts again in their entirety in order to produce a ‘skeleton’ of each interview. In subsequent re-readings, I noted any mention of symptoms and medication in the order in which they emerged during the interview. Having identified issues within and across transcripts, each cover analysis included sections on diagnosis, reaction to diagnosis and disclosure; the role of comparative suffering; the role of positivity; and how participants engaged (or not) with the idea of medical research. In addition to the cover sheet analyses, I produced tables outlining ‘diagnosis conversations’ as well as how participants spoke about medical research and their emotional responses underlying this point of their interview. I read transcripts in order to identify the different voices at play and questioned which, and whose, stories were guiding participants’ narratives at different stages. The more I engaged with my transcripts, the more it became possible to read them in order to hear the silences.

Thinking with participants’ stories involved thinking in terms of the ‘capacities of stories’ to do certain kinds of work (Frank 2010, p.74) and I found it helpful to ‘test’ participants’ illness narratives against some of the key ‘capacities’ identified by Frank (ibid. pp.27-42). As I read transcripts, I therefore thought and wrote about how participants’ stories both *made* trouble for them, but also how they *dealt* with their troubles (p.28). I thought about the way in which their stories ‘tested’ character, not least through revealing the degree to which participants resisted, embraced, or maybe failed to recognise the character into which they had been cast (p.29).

A story does not stand alone; it is always associated with other stories, and as I became increasingly familiar with my transcripts, I became more alert to the resonance both within and between participants’ stories. It was also important to read for contradictions within and between stories, as well as the capacity for stories to act in ways not anticipated by the teller (p.35).

Of immense poignancy in any narration of Parkinson’s is the capacity of stories for ‘suspense,’ described by Frank as resulting from a ‘tension between different possible outcomes – some to be hoped for and others to be feared’ (p.32). Reading

participants' transcripts through a lens of 'suspense' helped me focus on the different ways in which participants approached and reacted to the management of their symptoms through drugs; the medical and societal quest for a cure; the existence of deep brain stimulation as a possible treatment; the uncertain trajectory of Parkinson's with its capacity to be slow or fast progressing; and the possibility that Parkinson's may lead to considerable incapacity as well as dementia. Examining 'suspense' opened up the 'What ifs?' of stories.

3.13 Presentation of data: the three data chapters

If opening up analysis of participants' stories felt daunting, how best to represent them has been the ultimate challenge. Of course, the re-reading and analysis of transcripts has not only been undertaken according to DNA's five 'commitments' and the 'capacities of stories' outlined above, but also within the context of research already undertaken into Parkinson's (literature review) as well as reference to literature relating to chronic illness.

Consequently, 'data' is presented over three chapters comprising: the disease story; stories of diagnosis; and patient narratives. There are many different ways of undertaking DNA (Frank 2010, pp. 112-144) and for the purposes of this thesis I have experimented with different forms according to the analytic interest at the heart of each chapter.

3.13.1 The disease story: the 'story behind the story'

Fundamental to any dialogical narrative analysis lies the question of how a story may be both 'subjective' (the way in which the 'tellers' understand their world) and 'external' (stories also set the limits of what can be understood) (Frank 2012, p.46). The chief purpose of the first data chapter is to understand the overall narrative context in which any discussion of Parkinson's takes place. It experiments with the concept of dialogical narrative analysis by placing participants' voices into dialogue with the 'official' story of Parkinson's - itself a story that has shifted over time – paying close attention to the means by which individuals both narrate and respond to any external account, and exposing a story that, through its shape-shifting nature, resists being 'finalised.'

Once diagnosed with Parkinson's, participants' 'narrative habitus'⁹ changes as they are forced to seek new stories. Whether or not people are attracted, repelled or indifferent to certain stories, depends on an individual's 'disposition' (p.53). I have tried to illustrate this through placing participants' individual voices in dialogue not only with the external narrative of Parkinson's, but also with each other. At the same time, this practice makes apparent how individuals' voices are, indeed, 'resonant with the voices of specific others' (2012, p. 35). The latter may include medical professionals, those involved in scientific research, friends, family, support groups, fellow sufferers and, undeniably, the media.

Accordingly, by taking into account the personal, social and historical conditions that mediate people's stories (Josselson 2011, p.226), this first data chapter illustrates how individuals start to talk about their illness in response to an external disease narrative that is shaped by 'culturally shared stories' (Stephens 2011, p.67). At the same time, the multiple perspectives represented through any one voice lend complexity to the commonalities and differences within, and between, any narrations of the illness experience.

3.13.2 Diagnosis stories

As outlined above, in my role as researcher I have heard multiple stories about 'similar events or experiences' (Frank 2010, p.102). As analysis has proceeded, I have found that stories do, indeed, 'cluster into types' which 'become identifiable as they are named.' These names can 'describe the stories' (pp.120 & 121) and the starting point for this chapter has therefore been, quite simply, 'diagnosis stories.'

There is nothing 'neat' about a diagnosis of Parkinson's, and yet diagnosis stories – particularly the *moment* of diagnosis – have largely been ignored in the literature on Parkinson's. In the context of my participants' narratives, diagnosis stories cry out as being worthy of – and requiring – attention. They act both as 'stories *behind* stories' and 'stories *within* stories,' emerging from, and integral to, the overall illness story. Diagnosis is a story that reverberates throughout participants' narratives and is the moment to which many return as their account unfolds.

⁹ The core elements constituting narrative habitus include: knowing a corpus of stories, feeling comfortable telling and hearing certain stories but not others, and sharing with other people a sense of where events in a story are likely to lead (Frank, 2010, p.195).

I have been not been able to give voice to each and every diagnosis story, and remain aware that nobody ever has – nor should have - the ‘whole story’ (p.103). Nevertheless, I have worked to connect stories, foregrounding key voices against a supporting background cast. This second data chapter builds on the first, in turn preparing the way for a chapter representing narratives in their entirety.

3.13.3 Patient narratives: ‘a life less ordinary’

This final data chapter presents the narratives of three different participants: Rory, Keith and Sarah. Although it is clear that I could have ‘assembled and sorted’ my data in ‘multiple ways’ resulting in ‘different analyses,’ DNA is undertaken in a spirit of opening up and expanding dialogue rather than presenting any analysis as ‘the last word’ (Frank 2012, p.44). Thus, I make no claim that the narratives presented in this final chapter are either ‘typical’ or even ‘representative’ of the 37 stories I heard. Rather, the representative nature of Rory, Keith and Sarah’s stories may be found in ‘the generalised problem of telling a life story that includes a debilitating chronic disease’ (Frank 2010, p.116). Each story is unique. Each story also has a vividness that will, I hope, go some way to achieving the desire expressed by many participants, namely that ‘non-sufferers’ may begin to understand their ‘lived experience’ of Parkinson’s.

In order to structure the dialogical narrative analysis of my three participants’ narratives, I have drawn on Arthur Frank’s typology of illness. First outlined in his book, *The Wounded Storyteller* (1995), he proposed that ‘any unique story is fabricated through a weave of at least three core narratives’ (2010, p.118): restitution, chaos and quest. Thus, a narrative type is ‘the most general storyline that can be recognised underlying the plot and tensions of particular stories’ (1995, p.75). Frank himself has written extensively about these types (Frank 1995, 1998, 2002, 2004a, 2010, 2012, 2013) and, in addition, there now exists a small number of studies that have used, extended or adapted Frank’s typology.¹⁰ I make reference to some of these studies in the final two sections of this chapter where I first outline Frank’s typology (3.14) before briefly discussing how I use it within my own study (3.15). Finally, a broadly chronological^f table of all the studies that I have been able to locate, detailing the aims of the study and its design; the authors’ findings;

^f I have grouped studies by the same authors together.

limitations and some of my comments can be found at the end of this chapter (section 3.16 below).

3.14 Arthur Frank's typology of illness

3.14.1 Restitution

At its simplest, the restitution plot is: 'Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' (1995, p.77). This narrative type espouses the Parsonian 'sick role' with its emphasis on expectations and obligations around seeking treatment and getting better, or at least being restored to 'a reasonable approximation of the life that was led before the illness' (2012, p.47).

In Frank's experience, restitution stories 'predominate in the talk of the recently diagnosed' whereas 'the ideal of restitution recedes farthest into the background of stories of chronically ill persons' (1998, p.201). Indeed, Brody questions whether to include restitution as a narrative type by which to understand the experience of chronic illness might be considered contradictory – i.e. by definition, someone with a chronic illness can never return to 'just as they were before' and therefore 'things are never all right in the end' (2003, pp.85-6). He therefore proposes that the merit of speaking about restitution in relation to chronic illness is to be found in its adequacy at certain times of the illness course and as a means of providing 'psychological satisfaction to both teller and listener' (p.86).

I would argue that, for Frank, the inclusion of restitution as a narrative type for considering stories of chronic illness is less about 'psychological satisfaction' (although that may play a part) and more about understanding the societal and cultural *pressures* felt by chronically ill people. It is about inviting the analyst to pay close attention to a society in which restitution remains the 'culturally preferred narrative' and in which medicine is still driven by a 'single-minded telos of cure' (1995, pp.82-3). It is also about examining a situation in which 'the ill person's own desire for restitution is compounded by the expectation that other people want to hear restitution stories' (p.77), and it is about questioning the role of the restitution narrative in exerting pressure on people with chronic illness to be 'successfully ill' (1997, p.137). That these two positions might not be mutually exclusive is illustrated in one study examining the experience of men living with chronic pain

where the authors found that, although stories of restitution related to medical expertise, they also ran alongside stories expressing a ‘profound human need’ to ‘rebuild a self, be comforted and be connected’(Ahlsen, Mengshoel et al. 2012).

3.14.2 Chaos

Chaos is the antithesis of restitution, for its plot imagines life ‘never getting better’ (Frank, 1995, p.97). This tenet of chaos resonates particularly strongly with the experience of people with medically unexplained symptoms (MUS,) for whom illness has ‘no clear beginning’ and ‘no actual or imagined end’ (Nettleton, O'Malley et al. 2004, p.48), as well as people who are ‘living and dying’ with chronic obstructive pulmonary disease (COPD) (Pinnock et al, 2011). For Frank, chaos is indicative of ‘deepest illness’ and reflects lives ‘lived at the bottom of [a] funnel’ of problems (1998, p.202) and chaos narratives lack structure and are hard to listen to. Again, echoes of this can be heard in the stories of people with MUS, for whom there are ‘no route maps’ (Nettleton et al. 2004, p.206)), or people with COPD whose ‘chaotic stories’ were found to contrast with the ‘well-rehearsed’ stories of people with lung cancer (Pinnock et al. 2011).

Not only are chaos stories hard to listen to, they are also hard to ‘hear,’ since they remind the listener of their own human vulnerabilities and provoke ‘anxiety’(Frank 1995, pp.97-8). Chaos narratives are particularly hard for clinicians (p.111) since they reveal ‘vulnerability, futility and impotence’ emerging against the preferred backdrop of ‘remedy, progress and professionalism’(p.97) and the veracity of this claim is heard in the story of MUS, where there is no ‘identifiable pathological basis’ for illness, and in the story of COPD where people speak of no ‘expectation or hope of a cure.’ Thus, chaos narratives are not only indicative of the ill person’s loss of control, but also tell of ‘medicine’s inability to control the disease’(p.100). Consequently, as people are plunged deeper into chaos, the effects may be ‘felt at the bodily level’ and ‘embodied distress [may reshape] narratives’(Becker 1997, p.195).

For Brody, the term chaos narrative is ‘ambiguous,’ since it may mean a narrative that is chaotic in form (potentially anti-narrative) or a narrative that is *about* chaos (2003, p.87) and Frank, despite writing of ‘chaos stories as being told,’ suggests that they ‘cannot literally be told but can only be lived’ (1995, p.98). He extracts himself

from this analytical nightmare by proposing that if the chaotic story cannot be told, ‘the voice of chaos can be identified and a story reconstructed’ (pp. 98-9). However, with the chaos narrative, there is always the danger that this story is silenced (others do not want to listen) or that the sufferer is steered into another narrative type. Frank warns against the latter (e.g. redefining expressions of chaos as ‘depression’) since this is not only to deny what is being experienced, but also to dismiss chaos as ‘the patient’s personal malfunction’ (p.110) thereby ‘intensifying the suffering of whoever lives this narrative’(1998, p.202).

Even if the sufferer is not steered into another narrative type, an examination of responses to a chaos narrative told by a person with SCI showed just how difficult it was for the ‘listeners’ not to offer solutions to a situation that they perceived as intolerable (Smith and Sparkes 2011). The insight gained from this study has been helpful for reflecting on how I responded to my own participants’ stories, and the importance of not, unwittingly, ‘intensifying suffering.’ To this end, Frank is clear that the chaos story must be heard, for ‘to deny a chaos story is to deny the *person* telling the story,’ preventing them from becoming ‘participants in empathic relations of care’(1995, p.109).

3.14.3 Quest

As already stated, DNA is committed to the view that ‘any individual voice is actually a dialogue between voices’ (2012, p.34), and for Frank it is the quest narrative that ‘affords the ill their most distinctive voice.’ For Brody, it is the narrative type most like a ‘traditional fairy tale’ and it has been shown to play a key role in ‘people’s efforts to restore a sense of continuity after serious illness’ (2003, p.88). In Frank’s view, quest is ‘defined by the ill person’s belief that something is to be gained through the experience’ even if ‘what is quested for may never be clear’(1995, p.115). At the same time, he identified three ‘facets’ of the quest narrative: memoir, manifesto and automythology.

a) Memoir

This is the gentlest form of quest story in which a person incorporates illness into their life and the story is told stoically with no special insight claimed (pp. 119-120).

b) Manifesto

On the other hand, ‘manifesto’ is the least gentle form of quest story. In this narrative telling, silence is the enemy; there is a truth to be told. Illness is a social issue and a person may call for social action and change (pp. 120-122).

c) Automythology

Frank uses the metaphor of the phoenix to describe this form of quest narrative. It is one in which the survivor is ‘reborn’ and acquires a new identity through self-reinvention. Emphasis is on individual change rather than social reform (pp. 122-126).

Fundamentally, the quest narrative (in any of its forms) is not to be confused with a search for restitution. Rather, it is a search for what the ill person can ‘reclaim’ of life; what they can learn; what insights they can gain; and what they can pass on to others ‘who have not made their journey’ (1998, pp.204-5). Whereas restitution stories belong in scientific journals (after all, for the ill person ‘illness is nothing in particular to talk about once one is cured’ (p.201), most published autobiographical accounts of illness are quest stories (1995, p.115). Of course, since the first edition of *The Wounded Storyteller*, there has been an exponential rise in the number of published and self-published accounts of illness in books, newspapers and on the internet through blogs and other sites. However, initial research into how people engage with illness through these diverse media sources suggests that Frank’s supposition about quest stories holds true – i.e. an analysis of cancer patients’ use of the internet showed that their interactions with others in the virtual environment typified the ‘quest narrative’ (Nettleton 2010, p.83).

3.15 Use of Frank’s typology in this research study

Frank has himself stated that a typology should not be considered as ‘final’ or ‘closed’ (2010, p.121), but rather something to which other types might be added if deemed necessary or helpful. He has also acknowledged the dangers inherent in using a typology – namely that, as researcher, one may try and ‘fit’ stories into a framework that then creates a ‘general unifying view’ rather than reflecting the ‘particularity of individual experience’ (Frank 1995, p.76). This is something to which I have tried to remain alert, and it has therefore been helpful see how this ‘danger’ might manifest itself within a piece of research. For example, a study

(n.17) into the lived experience of chronic fatigue syndrome (CFS) identified a single trajectory in participants' illness narratives, i.e. 'restitution, moving to chaos, back to restitution and then on to quest' (Whitehead, 2006), thereby leaving itself vulnerable to accusations of creating a 'general unifying view' (op. cit.) and imposing 'closure' on what can be heard in people's stories. Similarly, the use of a matrix to assess the different narrative genres adopted by stroke survivors (France et al, 2013) resulted in the feeling that stories might become exemplars of narrative types, rather than narrative types being used to interpret the way in which stories work for the teller (Frank, 2010, p.120).

Frank further emphasises that, in the telling, any illness story will not 'conform exclusively to any of the three narratives' but rather 'combine all three, each perpetually interrupting the other two' (1995, p.76). A number of studies have usefully illustrated how this can manifest itself in a variety of ways. For example, a study exploring the experience of chronic pain found that men's stories did not conform exclusively to one narrative type, although one type might be 'more significant' during the telling (Ahlsen, Mengshoel et al. 2012). Another study focusing on the experience of aphasia also found that people used 'different narratives types at different times,' but did not concur with the view that one type was more significant than another (Mitchell, Skirton et al. 2011). Indeed, the complexity of some narrative tellings in a study examining the experience of HIV led the author to introduce a new 'type' – 'polyphonic narratives,' characterised as they were by 'overlaid, interwoven and often contradictory stories and values' (Ezzy 2000, p.613).

Finally, a typology is not 'an end in itself' (Frank 2012, p.49) and types 'are of narratives, not people' (2010, p.119); they are not descriptions of 'personalities' but rather a means of establishing, even expanding, the narrative resources available to ill people (2012, p.47). How this might be achieved in practice is illustrated by a study examining the views of people with MND, in which the authors created their own typology, nevertheless acknowledging and drawing on the principles outlined by Frank. Thus, they identified four types of narrative – 'sustaining,' 'enduring,' 'preserving' and 'fracturing' – but strongly emphasised that these were 'not representative of people's characters or stages of illness, but rather storylines that could be recognised' (Brown and Addington-Hall 2008, p.206).

It is therefore important to understand that my reason for using Frank's typology has been as a 'listening device' (1995, p.76), not simply a means of 'putting stories into boxes' (2010, p.119). I, too, have used this typology in order to pay close attention to the *kinds* of stories my participants tell and to hear how their stories 'mix and weave different narrative threads' (1995, p.76), at the same time recognising that different narrative threads might dominate my participants' discourse differently according to the day, as well as over time.

¹ Life as Narrative, 1987, p.13

² Doing Qualitative Research, 2005, p.178

³ Interviews for this study 'Choices and Control when you have a life-shortening illness: Researching the views of people with Motor Neurone Disease' started in November 2011 – exactly the same month in which I began my interviews in earnest. For an executive summary of the research, see: <http://www.mndassociation.org/Resources/MNDA/Life%20with%20MND/Documents/Choices%20and%20control%20Exec%20Summary.pdf>

⁴ Portage operates according to a code of practice set out by the National Portage Association (NPA). See <http://www.portage.org.uk/>

⁵ Page numbers refer to a word document copy of this chapter, accessible through <http://alumni.media.mit.edu/~brooks/storybiz/riessman.pdf>

⁶ LSVT is the Lee Silverman voice treatment - LOUD (LSVT LOUD) and is one of the most widely practised treatments for speech disorders associated with Parkinson's disease. For a history of its development, please see <http://www.ncvs.org/research/lsvt-history.html>

⁷ Professor Williams took this term, in turn, from Lofland, J. and L. Lofland (1971, 1984 & 1995) *Analysing Social Settings: a Guide to Qualitative Observation and Analysis*. Belmont, Wadsworth. Please see p. 778 of Ehrlich, K., et al. (2008). "The embryo as moral work object: PGD/IVF staff views and experiences." *Sociology of Health & Illness* 30(5): 772–787.

⁸ This term is used by Colbourne and Sque in their work exploring the potential therapeutic impact of qualitative research interviews. The phrase is, in turn, taken from work undertaken by Janice Morse. See Colbourne, L. and M. Sque (2005). "The culture of cancer and the therapeutic impact of qualitative research interviews." *Journal of Research in Nursing* 10(5): 551-567.

⁹ Arthur Frank uses this quote from Bruce de Silva, 'Endings' (2007) as an epigraph to the first chapter of his book, *Letting Stories Breathe* (2010, p.20).

¹⁰ The most cohesive body of work drawing on Arthur Frank's ideas and concepts is that of Brett Smith & Andrew Sparkes who, using the same data, have written a number of articles about the experience of spinal cord injury (SCI). Their work powerfully illustrates how new insights might be yielded by changing the lens through which one views the same information. For the purposes of the table (3.16) I have focused on the three studies that have made the most direct use of Frank's restitution, chaos and quest typology.

3.16 Table of studies referencing Arthur Frank's typology (2000-2014)

Author, Year, Country	Aim, design, methods	Findings	Comments & limitations
<p>Ezzy 2000 (Australia)</p> <p><i>"Illness narratives: time, hope and HIV."</i></p>	<p>Establish how people living with HIV/Aids (PLWHA) make sense of their illness experience.</p> <p>Dual methodology using a quantitative survey as well as 45 qualitative interviews.</p> <p>For the qualitative part of the study, the author undertook a narrative analysis using a typology (based on Arthur Frank and also Michele Davies) and identifying the dominant narrative structure around which each interview was formed. It focused on each person's current self-understanding as presented in the interview.</p> <p>The author states that the typology was developed inductively through:</p> <ol style="list-style-type: none"> 1. Detailed reflection on characteristics of each narrative 2. Comparison of narratives 3. Grouping into similar types based on shared temporal orientations and plot structure 	<p>Found three main types of narrative which the author called:</p> <ol style="list-style-type: none"> 1. Linear restitution narratives (LRN) 2. Linear chaos narratives (LCN) 3. Polyphonic narratives (PN) <p>LRNs -characterised by: "life as normal" and the continuation of values and goals held previously. There is a faith in medical science. Hope focused on concrete outcomes (improved health, material possessions).</p> <p>LCNs -characterised by expressions of depression, anger, isolation, social dislocation.</p> <p>PNs -Oriented toward the present, emphasising the unpredictability of the future. Contradictory stories and values. Hope is abstract. (Similar to Frank's quest narratives) they might recount increased self-understanding and the gaining of new insights as a consequence of their illness</p>	<p>A small point, but numbers did not quite add up. The author stated that 45 interviews were undertaken, and yet spoke about participation by 8 women and 38 men.</p> <p>Used the typology 'thematically' whereby different aspects of each narrative type are illustrated by quotes.</p> <p>The study took on a 'quantitative' feel: i.e. the author broke participants' narratives into 'main types' suggesting 38% were linear restitution; 27% linear chaos and 31% polyphonic and 4% did not fall into any of the above categories. Through quantification the study ran the risk of these types becoming more real than the story (Frank, 2010, p.119). The individual nature of narrative was somewhat lost as participants' stories were used to 'fit' the typology.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments & limitations
<p>Thomas-MacLean 2004 (Canada)</p> <p><i>"Understanding breast cancer stories via Frank's narrative types."</i></p>	<p>Enhance understanding of embodiment after breast cancer through Frank's narrative types.</p> <p>One focus group discussion (five women) and two in-depth interviews with each of 12 women who had experienced breast cancer.</p> <p>Age ranged from 42-77. Length of time since diagnosis, 1 year to 24 years.</p>	<p>Restitution was the story form most desired by participants, whereas only 3 of the 12 narratives were 'truly' representative of the quest narrative. The chaos narrative was prominent when speaking about bodily difficulties and the involvement of other people in their lives. Chaos narratives were often contained within the other two forms of narrative.</p>	<p>The study highlighted restitution, quest and chaos within breast cancer narratives, but did not present any narratives as a whole. Thus, the reader was encouraged to generalise about the illness experience where certain narrative types might be heard.</p> <p>None of the women in the study had elected to have reconstructive surgery. Authors felt this may have affected some participants' attitude towards 'restitution.'</p>
<p>Nettleton, O'Malley et al. 2004 (UK)</p> <p><i>"Enigmatic illness: Narratives of Patients who Live with Medically Unexplained Symptoms."</i></p>	<p>Detailed exploration of two patient narratives arising from a broader study exploring the experience of 18 people (5 men, 13 women) living with medically unexplained symptoms and no clinical diagnosis.</p> <p>These 2 narratives were chosen for the psychological dimensions in the narration of their illness – one resisting psychological explanations, the other engaging with them.</p> <p>Analysis draws on Frank's typology.</p>	<p>Narratives told by people living with undiagnosed illness resonate with Frank's notion of chaos narrative. Stories have no 'route maps' – difficult to hear. With no identifiable pathological basis, medical practitioners are left impotent to treat or provide interventions. The absence of a diagnosis or medical explanation makes it difficult for people to make sense of their illness. Ultimately, patients have to get on with their lives on their own, leading to a feeling of isolation and neglect. Patient one: worked against the restitution narrative and felt that she must always prove that her illness was not 'psychological.'</p>	<p>Authors commented that all participants were recruited from a biomedical setting and retained a biomedical notion of illness. Therefore, interviews with patients committed to non-biomedical medicine may have different stories to tell.</p> <p>By exploring two narratives in depth, it became possible to hear the 'culturally available discourses' as well as details about the narrator's life.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments & limitations
		Patient two: took refuge in psychological explanations given that no other explanation was forthcoming.	
<p>Nettleton, Watt et al. 2005 (UK)</p> <p><i>"Understanding the narratives of people who live with medically unexplained illness."</i></p>	<p>Exploration of the narratives of patients living with medically unexplained symptoms (MUS)</p> <p>18 participants, 5 men and 13 women. Recruited from hospital neurology outpatients department. Aged 28-67. Duration of symptoms ranged from 3 – 25 years.</p> <p>Narrative analysis for content (reading transcripts for issues within and across transcripts) and structure (using Frank's typology to analyse 'forms of telling.')</p>	<p>Three main features were identified:</p> <p>Most narratives were chaotic in structure.</p> <p>Many expressed the concern that symptoms may be 'all in the mind' (psychological).</p> <p>They expressed the view that they were 'medical orphans.'</p>	<p>Authors noted that participants were drawn from a single specialty - possible bias arising from the fact they were willing and able to talk about their experiences.</p> <p>Nobody was from a black or minority ethnic groups.</p> <p>Nobody seeking help only from complementary practitioners was involved.</p>
<p>Nettleton 2006 (UK)</p> <p><i>"I just want permission to be ill": Towards a sociology of medically unexplained symptoms."</i></p>	<p>Further thematic analysis using data from the same study (2005 above).</p> <p>Aim of this study was primarily conceptual, integrating the findings of the empirical analysis with the existing literature (on MUS and unexplained pain).</p>	<p>Findings broadly concur with those in the related literature – difficulties of living with uncertainty; dealing with legitimacy; resistance to psychological explanations of their suffering.</p> <p>This study elaborated on 3 related issues, named: Morality (the need to have symptoms acknowledged as genuine).</p>	<p>All 3 papers on MUS, read together, result in a particularly useful study for revealing social discourse around unexplained illness. Above all, patient narratives revealed the paradox around 'medical uncertainty': that the more advanced medical technologies become, the less</p>

Author, Year, Country	Aim, design, methods	Findings	Comments & limitations
		<p>Chaos (no clear beginning and no actual or imagined end).</p> <p>Ambivalence (towards medicine as a consequence of having an ‘enigmatic’ body).</p>	<p>able society is to tolerate clinical uncertainties. This results in people with MUS having to account for themselves; making an effort towards ‘restitution’; finding that society is not only uncomfortable with this medical anomaly – but fearful of it.</p>
<p>Smith, B. and A. Sparkes (2004). (UK)</p> <p><i>"Men, sport, and spinal cord injury: an analysis of metaphors and narrative types."</i></p>	<ol style="list-style-type: none"> 1. Explore most common metaphors used by men in telling their stories post spinal cord injury (SCI). 2. Focus on the manner in which this is shaped by three narrative types. 3. Explore the implications of this dynamic process for their identity reconstruction as disabled men. <p>Life stories of fourteen, white, predominantly working-class men, aged between 26 and 51. Age when they sustained SCI ranged from 16 to 35. All were involved in confidential, thematic, informal, life history interviews conducted in their homes by the primary investigator.</p>	<p>All the men drew on metaphors to help understand and impose order on their embodied experiences. There were significant differences in the actual metaphors used and the influences of these in reconstructing body-self relationships.</p> <p>The differences in metaphors used were attributed to the power of the restitution, chaos & quest narratives to shape experience in general and, more particularly, the metaphors used in personal accounts.</p> <p>Sporting or ‘war’ metaphors predominated in 11 stories framed by the restitution narrative. This made it difficult to develop different senses of self and explore alternative body metaphors and narratives.</p>	<p>The authors emphasised that their findings were ‘illuminative rather than definitive.’</p> <p>Suggested further exploration needed into metaphors used and understood by other disabled men.</p> <p>The metaphors identified in this study arose in the context of an interactive interview, thus research examining use of metaphor in different contexts and conditions may be helpful.</p> <p>Nevertheless, the use of metaphors matter and need to be taken seriously.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments & limitations
	<p>Each participant - interviewed three times (each interview lasting from 2-5 hours). All interviews were tape-recorded and transcribed verbatim.</p> <p>Structural (formal plot and organisation) and content (central themes within the narratives) analysis was carried out.</p>	<p>One participant's life 'was, and remained in, chaos.' Life was metaphorically storied as choking, in solid darkness, an emotionally brittle object. Constructing any sense of self or exploring any other identity was extremely problematic² participants framed their stories as quest narratives, i.e. they met suffering head on, accepted impairment and disability and sought to use it. They used 'journey' metaphors. The authors felt that these enabled a developing self and a more communicative body to emerge that was willing to explore different identities and possible selves.</p>	
<p>Smith, B. and A. Sparkes (2005) (UK)</p> <p><i>"Men, sport, spinal cord injury, and narratives of hope."</i></p>	<p>Explore the meanings of hope in the lives of men living with SCI. (Based on same data set as above)</p>	<p>The kinds of hope used by the men in the study were shaped by three powerful narrative types that circulate in Western culture. The authors defined these as:</p> <ol style="list-style-type: none"> 1. Concrete hope, shaped by the restitution narrative. 2. Transcendent hope, shaped by the quest narrative. 3. Despair or loss of any hope, shaped by the chaos narrative. 2. Findings in line with the above study – i.e. kinds of hope were shaped by power of narrative types. 	<p>As above, the authors suggest their findings are illuminative rather than definitive and are therefore a point of departure for further investigation.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments & limitations
		<p>Different from the above study was the question raised by authors questioning whether 'hope' was important to the men or whether it was something they felt they were 'supposed' to talk about. Expressing hope may have been in order to maintain relationships and secure professional services.</p>	
<p>Smith, B. and A. Sparkes (2011) (UK)</p> <p><i>"Exploring multiple responses to a chaos narrative."</i></p>	<p>Tellability and tellership: Presentation of the four most common responses to a chaos narrative as told by a man with SCI. Based on one of the interviews gathered in the 'life story' study (above) of people living with SCI.</p> <p>This article evolved as a consequence of the authors' interest in the reactions they received to the sharing and disseminating of their findings.</p>	<p>Four most common responses:</p> <ol style="list-style-type: none"> 1. Depression-therapy restitution story (the teller needs to move out of chaos, is depressed, needs therapy). 2. Breakthrough restitution story (the teller needs to move out of chaos. There will be a cure. Teller should be optimistic re stem cell treatment. Optimism will beat the chaos). 3. Social model stories (the teller needs to move out of chaos, but the chaos he is living is due to the barriers 'out there' in society). 4. Solace stories (the teller needs to move out of chaos. Listeners should listen and empathise). <p>All responses agree that chaos is no way to live. Each suggests a different way of how to emerge from it. Each response contains problems (discussed by authors).</p>	<p>Relied heavily on people's verbal responses - authors acknowledge that words can feel inadequate for conveying 'raw emotional reactions' elicited by chaos.</p> <p>It would be useful to attend to what we do not say – 'the multiple meanings of silence' as well as bodily communications.</p> <p>Analysis did not pay particular attention to people's narrative environments and the impact that may have had on their responses.</p> <p>The authors highlight that Jamie's voice (the teller of the chaos story) is conspicuous for its absence 'in terms of responses' – how might he respond to all the responses to his story?</p>

Author, Year, Country	Aim, design, methods	Findings	Comments & limitations
<p>Whitehead 2006 (UK)</p> <p><i>“Quest, chaos and restitution: Living with Chronic fatigue syndrome/myalgic encephalomyelitis.”</i></p>	<p>Explore how people with CFS/ME describe and interpret their illness experience.</p> <p>17 interviews; 6 men and 11 women, aged 13-63 recruited from a number of settings.</p> <p>Analysis of interviews using Frank’s typology of illness (restitution, quest, chaos).</p>	<p>That people living with CFS/ME differ to those presented by people who are HIV positive or those treated for breast cancer (Ezzy, 2000 & Thomas-MacLean, 2004).</p> <p>Identified a trajectory in illness narratives for people with CFS/ME: i.e. people experienced restitution, moving to chaos, back to restitution and then on to quest.</p>	<p>No mention of ethical clearance.</p> <p>This study used Frank’s typology as a framework into which ‘the story’ of CFS/ME was fitted, thereby creating a ‘general unifying view’ rather than reflecting the ‘particularity of individual experience’ (Frank 1995, p.76). By establishing a trajectory for CFS/ME, it encouraged a generalisation of narrative types according to illness, rather than encouraging close attention to the type of story dominating an individual’s narrative on any one day.</p>
<p>Barrow 2008 (Ireland)</p> <p><i>“Listening to the voice of living life with aphasia: Anne’s story.”</i></p>	<p>*Explore and identify the role that narratives of disability (i.e. the ‘inner stories we live by’) play in how a woman with aphasia (Anne) and those close to her, make sense of stroke and aphasia.</p> <p>*Qualitative analyses (Framework) of in-depth interviews, of notes from participant observation, and of artefactual material.</p> <p>*Draws on Frank’s typology as well as medical and social models of disability.</p>	<p>Narratives of ‘limited competence’ and ‘disability as less than whole’ emerged as strong voices that stemmed from cultural and societal views about disability.</p> <p>In response to this Anne and other participants sought refuge in the ‘grand’ narrative of modern medicine with its focus on restitution, in order to make sense of their situation and to chart a way forward. As a result her life revolved around activities that would ‘make her better.’</p>	<p>I could not find any reference to ethics clearance/approval.</p> <p>An interesting study that reflected the tension arising for the researcher knowing both health professional’s ‘knowledge’ of Anne’s condition vs. the narrative ‘type’ that she was ‘trapped’ in. Whilst saying how important it is to ‘hear’ people’s narrative – it also reflected the author’s desire to change the narrative.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments
<p>Brown and Addington-Hall 2008 (UK)</p> <p><i>“How people with motor neurone disease talk about living with their illness: a narrative study.”</i></p>	<p>Explore how patients talk about living and coping with MND in order to develop approaches to understanding how individuals deal with problems of neurological illness, even while dying.</p> <p>13 adults, recruited through purposeful sampling. Longitudinal narrative interviews conducted at three monthly intervals over 18 months.</p> <p>Analysis focused on form and content of patient narratives. Drawing on Frank’s work, aimed to identify the types of storyline used by people with MND.</p> <p>Storylines illustrated through individual stories.</p>	<p>Four consistent types of narrative or storylines were identified:</p> <ol style="list-style-type: none"> 1. Sustaining (living as well as possible/active/engaged). 2. Enduring (disempowered/unable to fight for life or against death). 3. Preserving (about survival). 4. Fracturing (loss and fear of what is to come). <p>These were not representative of people’s characters or stages of illness but rather storylines that could be recognised.</p>	<p>Authors did not claim that the four storylines exhausted all possibilities or that they were necessarily generalizable.</p> <p>Of the four chosen stories used to represent the different storylines, the authors explained that they did not examine the differences of presentations of MND or differences in the stage of symptom presentation. These could have influenced the way in which storylines were constructed. Important contribution to a sparse literature, and helpful for promoting not only <i>a means</i> of paying close attention to how people with MND narrate their illness experience – but also raising an awareness of the <i>importance</i> of listening to how people narrate their experience.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments
<p>Vroman, Warner et al. 2009 (USA)</p> <p><i>"Now let me tell you in my own words: narratives of acute and chronic low back pain."</i></p>	<p>Explore the broader experience (acute as well as chronic) of low back pain (LBP) in the community. Qualitative data was collected during a wider Personal Project Analysis (PPA). Stories were written – in response to a final question in the PPA inviting them tell their story of back pain.</p> <p>133/143 participants answered the open-ended question. Aged 19-83. Thematic content analysis and structural analysis using Frank's illness typology.</p>	<p>The authors found that narratives were told solely as chaos narratives. Two themes emerged: the challenges to the authenticity of LBP and the consequences of living with LBP. From these two themes emerged 2 threads: the disruption of life due to physical limitations and the emotional distress incurred.</p> <p>The authors found that the chaos narratives provided insight into ways to improve the quality of interactions between patients and health care providers, particularly the need for healthcare professionals to 'accept' people's stories and their 'need to tell them' as well as listen to them without 'moving quickly to action.'</p>	<p>Authors acknowledged the absence of a 'pre-existing theoretical position' for the collection of the qualitative data, arguing that thematic analysis and narrative types provided 'flexibility.'</p> <p>It was interesting that, given the number of stories analysed, only one type of story was reported – chaos.</p>
<p>Mitchell, Skirton et al. 2011 (UK)</p> <p><i>"Amelioration, regeneration, acquiescent and discordant: an exploration of narrative types and metaphor used in people with aphasia."</i></p>	<p>With reference to Frank's narrative typology, explore the narrative types and metaphors used by people with aphasia.</p> <ol style="list-style-type: none"> 1. Investigate the different narrative types and plot lines used; 2. Explore the links between their use of narrative types /metaphors; 3. Suggest possible implications of the findings for reconstructing self-identities 	<p>Four distinctive narrative types were identified: amelioration (closest to restitution) discordant (closest to chaos), regeneration (closest to quest) and acquiescent (Frank's more recent illness as normal narrative type).</p> <p>Participants used different narrative types at different times, rather than one single narrative throughout.</p>	<p>At the end of the study the authors did acknowledge that different interpretations of MLEs could have produced different metaphorical concepts and therefore different analyses.</p> <p>Nevertheless, the rigid systematic style in which analysis was undertaken risked perpetuating a monological stance.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments
	<p>*11 participants. Video-recorded interviews in 2 phases: unstructured and semi-structured.</p> <p>*Analysed by coding plotlines and metaphorical linguistic expressions (MLEs), clustering the latter according to metaphorical concepts.</p> <p>*Coded the MLEs for the conceptual metaphors in order to facilitate the association of metaphorical concepts with narrative types.</p>		
<p>Pinnock, Kendall et al. 2011 (UK)</p> <p><i>"Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study."</i></p>	<p>To understand the perspectives of people with severe chronic obstructive pulmonary disease (COPD) as their illness progresses, and of their informal and professional carers, to inform provision of care for people living and dying with COPD. 21 patients, 13 informal carers and 18 professional carers. Up to 4 qualitative interviews with each patient and nominated carer over 18 months. (11 patients died during the study period.)</p>	<p>Researchers felt that people with COPD told 'chaotic' stories. They contrast this with the 'well-rehearsed' stories of people with lung cancer.</p> <p>They found no separation between illness narratives and life narratives. COPD is perceived as a way of life rather than an illness that disrupts life.</p> <p>They found that COPD lacked a public story – unlike cancer. As such – patients have no expectation of death and no despair, and equally no hope of cure.</p>	<p>No clear section re methodology.</p> <p>The study used Frank's typology in order to 'categorise patients' narratives' into 3 types.</p> <p>Study cohort may not have represented diversity of all those suffering from severe COPD. Nobody from ethnic minority and all were smokers or ex-smokers.</p> <p>Patients and informal carers were interviewed together which may have affected the way they told their stories.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments
	States that they took a thematic narrative approach and used categories informed by sociological theory on health and illness, such as Bury's work on biographical disruption and Frank's typology of illness.'	Findings challenge current assumptions underpinning provision of end of life care for people with COPD. The study found that 'a point of transition' to palliative care is meaningless and impractical in COPD.	
<p>Ahlsen, Mengshoel et al. 2012 (Norway)</p> <p><i>"Shelter from the storm: men with chronic pain and narratives from the rehabilitation clinic."</i></p>	<p>Examine the meaning of participating at a rehabilitation clinic in the lives of men with chronic neck/muscle pain (medically unexplained.)</p> <p>Qualitative interviews with 10 Norwegian men, aged 28-47.</p> <p>Narrative analysis used to focus on both the content and structure of men's stories and develop a typology.</p> <p>3 stories selected to 'represent' the typology- "because of their vividness."</p>	<p>The authors found that the meaning of being in rehabilitation extended far beyond treatment goals.</p> <p>Accounts 'revealed a strikingly positive image of the rehabilitation clinic.'</p> <p>Stories of restitution related to medical expertise, but at the same time three inter-related storylines emerged expressing a 'profound human need' to:</p> <ol style="list-style-type: none"> 1.Rebuild a self 2.Be comforted 3.Be connected <p>The authors found that their participants' stories did not conform exclusively to one type, although one type may be more significant during the telling.</p>	<p>An insightful study that listened carefully to a small number of male voices, enabling an understanding of the role of the rehabilitation clinic beyond its immediate stated treatment goals.</p> <p>Important to be aware of the potential for bias, given that participants were selected by physiotherapists at the clinic on the basis of their willingness to speak about their experience. Other perspectives may therefore have been missed.</p> <p>The interviewer (and primary author) was also a physiotherapist.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments
<p>Nosek, Powell Kennedy et al. 2012 (USA)</p> <p><i>“Chaos, restitution and quest’: one woman’s journey through menopause.”</i></p>	<p>Case study which emerged from a larger study (15 women) aiming to understand the experience of distress during menopause (papers have been published focusing on this).</p> <p>Aim was to present one woman’s transformational journey through menopause, analysed using Frank’s typology of chaos, restitution, and quest. In addition, her transcript was re-transcribed using Labov’s element of a true story and Gee’s poetic restructuring.</p> <p>The authors emphasise that the case study is not written in order to represent women’s experience of menopause in general, but rather provide in depth investigation of the complexity of a contemporary menopause experience. The story of this one woman was chosen as an ‘exemplar’ of the ‘transformational journey’ due to the intensity and depth of her experience.</p>	<p>Whilst menopause is neither an illness nor a disease, the authors found that Frank’s three narrative types – chaos, restitution and quest – together constituted their participant’s complete menopause story.</p> <p>The latter was told as a ‘journey’ starting with a complete breakdown in health (chaos); a long awaited but conflicting victory (restitution) and a deep search into the significance of her experience (quest).</p> <p>The authors found that this narrative revealed the complexities facing women at this stage of their lives. It highlighted social discourse around menopause and its symptoms, particularly social resistance to medicalisation and strong emphasis on self-healing. This might result in women (in the overall study) feeling confused and scared when faced with symptom management decisions; for the narrator in the case study, it left her feeling defeated.</p>	<p>A good example of Frank’s typology being used to help understand what the different stories were doing for the narrator, as well as revealing the social discourse surrounding the menopause in relation to health, medicine, femininity and ageing.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments
<p>France, Hunt et al. 2013 (UK)</p> <p><i>"Do Men's & Women's accounts of Surviving a Stroke Conform to Frank's Narrative Genres?"</i></p>	<p>*Explore the narrative types used by survivors of stroke, and understand whether their accounts were influenced by gender.</p> <p>*Secondary analysis of 18 transcripts (9 men and 9 women) taken from a larger sample.</p> <p>*Transcripts were matched according to stroke severity, how recently it had occurred, type of impairment, age and marital status. Frank's narrative types were used to identify dominant genres in each transcript.</p>	<p>Most respondents presented a single dominant or overarching 'genre.'</p> <p>The authors did not find that gender affected the type of genre adopted by a participant.</p> <p>Rather, the narrative type adopted in participants' talk was influenced more by stroke severity and the degree of anticipated or actual recovery.</p>	<p>The method of analysis used a matrix to assess the different genres used in people's accounts. This led to a sense that stories were served as exemplars of types rather than types used to help understand what the stories were doing for their narrators (Frank, 2010, p. 120).</p>
<p>Flynn, Daiches et al. 2014 (UK)</p> <p><i>"A post-transplant person': Narratives of heart and lung transplantation and intensive care delirium."</i></p>	<p>Explore the experience of Intensive Care Unit delirium.</p> <p>11 participants (7 men, 4 women); age ranging from 40-69, who had undergone different kinds of transplant. Recruited through outpatient heart and lung transplant services. Length of time between transplant and interview ranged from 6.5 months to 14 years. Findings of narrative analysis, including examination of narrative</p>	<p>Consistent with previous limited research, participants' stories were heavily influenced by the restitution narrative, although over time came the realisation that there was no return to 'normality.' Established a need for 'alternative discourses' (to restitution) perhaps through support groups. Participants felt responsible for the outcome of their transplants – i.e. responsible for its 'success' or 'failure.' Established a need for further research into compliance vs. personal responsibility.</p>	<p>By trying to understand the underlying narrative types used by people after transplant, this study revealed the limitations of narrative resources available to them. At the same time, recruitment may have prioritised people who attended more appointments and were therefore experiencing more difficulties, thereby affecting the narrative types upon which they drew.</p>

Author, Year, Country	Aim, design, methods	Findings	Comments
	‘types’ or ‘genres’ then presented as a ‘shared story.’	The study revealed considerable emotional and psychological distress might arise as a consequence of organ transplantation, including the experience of delirium. Established the need for better ‘psycho-education.’	
<p>O Malley-Keighran and Coleman 2014 (Ireland)</p> <p><i>"I am not a tragedy. I am full of hope': communication impairment narratives in newspapers."</i></p>	<p>To understand the types of personal narratives of communication impairments disseminated in Irish newspapers and understand how experiences of communication impairments are represented in these narratives.</p> <p>A qualitative study, using Frank’s illness typology, to analyse narratives published in 2 Irish national newspapers over 12 months.</p>	<p>The authors found that there was under-representation of communication impairments in Irish newspapers.</p> <p>6/10 narratives showed a combination of quest and chaos. 3/10 narratives showed a combination of chaos and restitution. 1 narrative was identified as being a quest narrative. 3 narratives contained elements of restitution.</p>	<p>I found this a confusing research paper. It was broken into so many sub-sections that maintaining any narrative thread while reading the paper was challenging. There was lack of clarity over which conditions they were to focus on and there was a statistical emphasis, despite its qualitative aim. It provided an example of a typology being used to put stories into boxes, thereby encouraging a monological stance ‘that the boxes are more real than the stories’ (Frank, 2010, p.119). The authors stated that peer reviewing ‘challenged their assumptions and biases’ as the external researcher ‘disputed certain themes.’ They did not elaborate on which themes.</p>

CHAPTER 4: THE DISEASE STORY

'This is what else you are connected to'
(Frank 2010, p.102)

4.1 Chapter outline

As outlined previously, this first data chapter experiments with the concept of dialogical narrative analysis by placing participants' voices into dialogue with the 'official' story of Parkinson's, itself a story that has shifted – and continues to shift – over time. In order to gain a sense of the history in which participants' stories are steeped, the chapter begins with a brief overview of the first known references of Parkinsonian symptoms (long before they were given that eponym) before moving to an official 21st century description of the disease. This sets the stage for participants' voices that, throughout the chapter, enter into a dialogue not only with 'official' accounts of their disease, but also with each other. The chapter concludes with a brief exploration of what happens to participants' stories as they come into dialogue with the contemporary and 'ongoing' voice of medical research.

4.2 Past stories

'In the Beginning': Historical References to 'The Shaking Palsy'

Although lauded for providing the first clear clinical description of the condition which now bears his name, it is generally agreed that James Parkinson was not recording a *new* disease (Stern 1989, Lees 2007, Goetz 2011). Indeed, some neurologists question whether it should be called a disease¹ at all (Calne 2002, Weiner 2008) and the literature remains confused on this subject. History is littered with references to symptoms that suggest Parkinsonism,^a dating as far back as Indian Ayurvedic texts compiled c 2500 BC;² Egyptian papyrus from c 1350-1200 BC, and Chinese medical texts dating from c 500 BC, as well as both the Old and New Testaments of the Bible, including a rather striking image from Luke (13:11) stating: *"There was a woman who for eighteen years had been crippled by a spirit; she was bent over, completely incapable of standing erect."*

Parkinson, in his Essay (1817), notes the particular contribution of Galen (c 129 – 200/210 AD), a Greek physician living in Rome, whose many medical treatises

^a "A group of conditions with the same core symptoms, one of which is now referred to as Parkinson's disease." (PD Nurse: personal communication, June 2011).

included one entitled “On tremor, palpitation, convulsion and shivering.” Although even today Parkinson’s is still frequently – although not exclusively - referred to as a movement disorder, it is fascinating to note that Galen had noted some of the *non-motor* symptoms associated with the condition, albeit suggesting them as causes rather than symptoms: “*It [tremor] is the impairment of the free exercise of one’s faculties... it is an unfortunate condition in which movement is unstable and not under one’s own control.... [caused by] mental distress, fear, muscular incapacity [and] mental depression.*” He further commented on something - today called ‘gait disorder’ - as being: “*a kind of paralysis which prevents people walking straight by mixing up the sides, exchanging left for right and right for left, failing to lift the foot and pulling it back instead, like those who walk up a steep incline*”(Stern 1989).

Perhaps one of the most memorable – almost lyrical - descriptions comes from Leonardo da Vinci,³ who not only described a condition akin to Parkinson’s, but also tried to work out what, physiologically, may be causing it, having noted: “*...how nerves sometimes operate by themselves without any command from other functioning parts of the soul. This is clearly apparent for you will see paralytics and those who are shivering and benumbed by cold move their trembling parts, such as their heads or hands without permission of the soul; which soul without all its forces cannot prevent these parts from trembling*” (Stern 1989, Calne 2002, Lees 2007).

Parkinson, whilst not mentioning Da Vinci’s description in his *Essay*, did deferentially acknowledge accounts by Galen, as well as other 17th and 18th Century physicians such as de la Boe, Juncker, Boissier de Sauvages and Cullen. These historical references suggest strongly that Parkinson’s (the disease) may have existed “for as long as human beings”⁴ and they are important in underlining that James Parkinson’s was not describing a condition caused by industrialisation (Lees 2007, Lees, Hardy et al. 2009).

The contention that Parkinson’s is *not* a product of industrialisation is further supported by the work of a Hungarian doctor, Ferenc Papai Pariz, writing 130 years before James Parkinson. Largely ignored in the medical literature due to its inaccessibility (it is in Hungarian), his medical text ‘Pax corporis’ (1690) contains a description of the four ‘cardinal signs’ of Parkinson’s (tremor, rigidity, slowness of movement, and postural instability). Indeed, the Hungarian neurologist, Daniel Bereczki, whilst acknowledging that Papai’s contribution is not as detailed and

focused as Parkinson's monograph, recently proposed that, for historical accuracy, his contribution "should be acknowledged in the future – even by changing the name of Parkinson's disease (PD) to Papai-Parkinson's disease (PPD)" (Berezki 2010).

Table 3 Historical references to Parkinson's disease

4.3 Parkinson's disease: an official 21st century story

Fast forwarding to the 21st century, the current NICE official guideline⁵ for the diagnosis and management (in primary and secondary care) of Parkinson's disease describes the condition thus:

'Parkinson's disease (PD) is a progressive neurodegenerative condition resulting from the death of the dopamine-containing cells of the substantia nigra. There is no consistently reliable test that can distinguish PD from other conditions that have similar clinical presentations. The diagnosis is primarily clinical, based on a history and examination.

People with PD classically present with the symptoms and signs associated with parkinsonism, namely bradykinesia, rigidity and rest tremor. Parkinsonism can also be caused by drugs, and conditions that are less common than PD. These include multiple cerebral infarction and degenerative conditions such as progressive supra-nuclear palsy (PSP) and multiple system atrophy (MSA).

Although PD is predominantly a movement disorder, other impairments frequently develop including psychiatric problems such as depression and dementia.

Autonomic disturbances and pain (which is rarely a presenting feature of PD) may later ensue, and the condition progresses to cause significant disability and handicap with impaired quality of life for the affected person. Family and carers may also be affected indirectly.

Health and resource implications

PD is a common, chronic, progressive neurological condition, estimated to affect 100–180 people per 100,000 of the population (between 6 and 11 people per 6000 of the general population in the UK) and has an annual incidence of 4–20 per 100,000. There is a rising prevalence with age and a higher prevalence and incidence of PD in males.^b

(From: Introduction to NICE clinical guideline 35, Parkinson's disease, issued June 2006).

^b See Appendix 8 for further information about the prevalence of Parkinson's.

4.4 ‘It takes a thousand voices to tell a single story’^c

From the moment I started my research I was told that Parkinson’s is a very ‘individual’ disease; that there are as many as 37, if not more, ‘associated’ symptoms, and that each person diagnosed with idiopathic Parkinson’s will have their own combination of symptoms. No two people will be the same.⁶ Indeed, at my first meeting with a Parkinson’s nurse specialist, he said: ‘I tell patients that if you go to a support group you won’t meet yourself.’ The following table offers extracts illustrating how the ‘individuality’ of symptoms becomes part of an ‘official’ narrative about Parkinson’s, feeding into individual stories about the experience of illness.

<p>Charles: ‘And what I did understand eventually, both from the consultant and discussing it with other people was that - and reading - was that the manifestations of Parkinson’s are very different from one individual patient to another....There’s no general – there may be an overall vague pattern, but they do vary so much.’</p>
<p>Zoe: ‘I registered on forums, I read people’s posts –and it was probably a good thing to try and understand it but a bad thing to try and understand it from that perspective because Parkinson’s is so individual that there’s no telling exactly what your prognosis is...’</p>
<p>Colin: ‘I know no two people who have got Parkinson’s the same, but the characteristics of the way it’s tackled can be the same.’</p>
<p>Keith: ‘It’s like cancer. There’s so many different types of cancer - and yet there’s no two Par, Parkinson’s sufferers the same [...] Yet we’ve only got one name for it.’</p>
<p>Ted: ‘Not every Parkinson’s has got the same thing [...] I met somebody in the village yesterday, he’s got difficulty, difficulty can’t speak and he’s only had it for 2 years. He’s lost, he can’t write at all, I can still write a little bit and mine’s 5 years diagnosis, 4 years...’</p>
<p>Edna (unable to walk herself, and never affected by a tremor, she comments on a friend) ‘But he can still get ...with a walking frame [...] can still get to the toilet. He can’t undo his trousers – that must be horrible, but of course he’s 90 odd and he’s only just started – well, a few years ago.... diagnosis. No two people are the same.</p> <p>J: No, no. ‘I mean some people shake all the time, don’t they?’</p>

Table 4 ‘No two people are the same’

^c A Native American saying.

Serendipity has resulted in my interviewing the same number of people with Parkinson's as there are, purportedly, symptoms. This, of course, means that I have been privileged to hear 37 individual accounts of what it can mean to live with a diagnosis of Parkinson's in the second decade of the 21st century. As with their combination of symptoms, each illness story is unique to the teller. And yet the story told is not entirely the teller's own, for 'stories depend on other stories' as well as the narrative resources available; each story is 'composed from fragments of *previous stories*, artfully rearranged but never original' (Frank 2010, p.119, 2012, p.35). In addition, stories are played out in the context of other stories that 'include societies, cultures, families or other intersecting plotlines in a person's life' (Josselson 2011, p.224). At the same time, no matter how they have chosen to mediate their illness experience, my participants' stories are crafted and enacted within a 'master narrative' that is shared by all – their 'encounter' with Parkinson's (Gatt-Rutter 2012, p.424). In the words of my participant Julian, diagnosed with Parkinson's in his forties: *'We're all very different [symptomatically] yet we all have the same tag, so, you know, whether we like it or not, we all have Parkinson's.'*

4.5 'You can't understand what it's like to be sitting this side of the table'

In attempting to represent and understand this 'master narrative' I have found myself driven very much by the desire to communicate with my participants, who have been the major source of information for this study and to whom I feel a sense of responsibility in both reporting and returning the information. It is their voices that continually resonate in my head as I commit words to paper. One such voice is Bill's. Bill was my 37th and final participant who, as we concluded the interview, politely reminded me that:

'You've interviewed 36 people who have all got Parkinson's, but you haven't. So you can't understand what it's like to be sitting this side of the table. You can hear the words, but you can't feel that. You have no concept. You've got the words, you can theorise, but until you, let's hope you never get it, but unless you've actually got it, you don't – it's not in here' (taps his head).

He is right. I do not have Parkinson's. I cannot know what it is like. I have, though, heard 'multiple stories about similar [...] experiences' and, as discussed in my Methodology chapter, the point of my analysis is not only to connect these stories but also to 'expand the dialogue' (Frank 2010, p.102). Through observing participants, and listening closely to their words, I hope in this chapter to 'reassemble' the external story of Parkinson's that lies behind the individual stories. It is a story that does not appear whole in any one interview but rather is 'remembered [...] in fragments' (ibid). By piecing together these fragments, alongside official medical and historical accounts, I hope to reveal not only the way in which multiple voices find expression within a single speaker's voice, but also how these voices both merge with, and also contest, each other (Frank 2012, p.35).

4.6 What's in a name?⁷

As someone originally trained as a historian, I declare a particular fascination in how our knowledge and interpretation of the past affects our own day-to-day experiences; how not only do 'stories echo other stories' but 'stories are [...] told to be echoed in future stories' (Frank 2010, p.37). For my participants, the word 'Parkinson's' is not simply a label for a particular set of symptoms, but rather, as Toombs⁸ asserts, a name that carries 'powerful symbolic significance' resulting in the need to 'confront the personal and cultural meanings associated with the disorder' (Toombs 1995a).

This is particularly apparent in Sarah's narrative.^d Although some other participants express unease with the name of their disease (see below) it is Sarah who finds it unusually troubling. About ten minutes into her interview she mentions her feelings about the name of the condition with which she now wrestles every waking moment:

'I remember going through a stage of not... of ignoring it. I used to take my daughter to school, drop her off, I was still driving then. I was okay then. I don't drive now. I used to drop her off at school, go to Gregg's and get two fattening sausage rolls, a newspaper and sit all morning and do the crossword and eat and that's all I used to do, for fifteen months that's all I did. I did work in the afternoon, a bit of washing. Then I pulled myself together and decorated the whole house. I would go from the sublime to the ridiculous. I don't know why that was, just getting

^d Sarah's narrative is discussed in greater detail in Chapter 6.

used to the idea I suppose. I didn't want to have it, I didn't like the name Parkinson's, didn't like the word.... I'd rather have had MS⁹ cos it sounds better.'

Jean, diagnosed not long before I interviewed her, said: 'I mean to start with, umm, I remember... the word Parkinson's I didn't like (she laughs)... It didn't, no, I thought Parkinson's, no - there's something about it, you know, and I suppose to start with it was difficult to say, yes, it was a bit difficult to say.'

Angela's GP referred her to a neurologist, thinking she may have had a stroke: 'He said 'it's *definitely not a stroke, but it could be a brain tumour or it could be Parkinson's.*' On asking Angela her reaction to this news, she said: 'Well, what I actually said to the neurologist- and I can't believe I did [...] I said, 'Let's hope it's a brain tumour because they can probably just chop that out,' whereas Parkinson's to me sounded like, you know, an horrendous thing. But the brain tumour sounded like, well it might – oh he did actually say a benign brain tumour, which I thought was a strange thing to say because how would he know before he looked at it whether it was benign or malignant? Anyway he said it could be a benign brain tumour or it could be Parkinson's. And I definitely opted for the brain tumour option. So that gives you some indication of how I felt about Parkinson's.'

Table 5 Participants' reaction to the name Parkinson's

Sarah's words instantly take me back to the moment when, five years previously, my son and I participated in a Stage II assessment to determine whether or not he was on the autistic spectrum. While the paediatrician, speech therapist and clinical psychologist discussed their various findings and observations, I was sent with Sam to await our fate in a parents' room. I took solace in a particularly sweet cup of tea as I sat on a sofa opposite a beech effect bookcase laden with blue folders. I chose one from the row of alphabetically arranged 'conditions'. I deliberately ignored autism. Dyspraxia became my diagnosis of choice.

On return to the consulting room, I tried to foretell any diagnosis from their facial expressions - perhaps there would not be one. I sat down, aware of an unnerving silence. Only minutes previously the room must have been filled with deliberating voices. A conversation began and I remember suggesting they may like to diagnose dyspraxia or Asperger's.¹⁰ I even handed the paediatrician a couple of pages about the latter, downloaded from the internet.

I thought that the paediatrician was saying no, he didn't have autism, only to realise that she was saying no to Asperger's: such a diagnosis was not possible as he had not used speech in his first three years. Then followed the words that changed our world: *'...so we believe he shows classic signs of being on the autistic spectrum.'*

I think I smiled and said thank you as we left.

4.6.1 'Why don't they call it James' disease?'

"Rose is a rose is a rose is a rose"
(Stein 1922).

I did not tell Sarah the effect her words had on me; how they momentarily transported me to my own story of five years previously. Instead, I recount my story here in an awareness that dialogical interpretation 'begins with the interpreter's recognition of being caught up in [...] her own stories' (Frank 2010, p.96). Hearing Sarah express the desire for a different name for her disease felt immediately familiar to me in that moment of the interview; there was a brief sense of 'overlap' through shared 'narrative habitus.'

In hindsight, my own preference for a different diagnosis for my son stemmed from anxieties related not only to how I would cope on a daily basis (dyspraxia seemed much less terrifying to me) but also to negotiating the reactions of others, influenced as we are by a social and cultural 'acceptability' of certain conditions. I have noticed, for example, that Asperger's brings with it 'kudos' and even talk of genius,¹¹ whilst autism brings with it a deep sense of the unknown, the unfathomable and a lingering sense of blame.¹²

4.6.2 Stories are good at reconnecting that which is always drifting apart

(Frank 2010, p.83)

What a diagnosis of Parkinson's 'brings with it' will, I hope, be revealed as this thesis unfolds. Of course, the views of my participants are particular to them; any one view cannot be representative of all. However, by putting their different and differing views into dialogue with each other, I hope to 'offer participants new perspectives on their stories and their lives'(Frank 2010, p.102).

On asking Sarah what it is about the name Parkinson's she does not like, she describes her upset as relating in part to the sound of the word – one with which she and her identity are now indelibly linked given its use to specify her condition:

'I don't know about the word, Parkinson's is not a very nice word, it's **harsh** and I'm not a harsh person. It's a ridiculous thing to say but that's how I felt, I don't like the name. Why don't they call it James' disease? It was James Parkinson wasn't it?'

Although Sarah speculates that 'James' may sound less harsh than 'Parkinson's, it becomes apparent that her upset is about so much more than the sound of the word. Rather, it is located in a past story (please see Figure 5 below) that has the capacity to haunt and shape her present experience and understanding. It is a story that arouses the imagination and emotions; that makes the unseen visible (Frank 2010, p.41) and for Sarah it is a story that holds particularly menacing connotations:

'James Parkinson – that's why they named it Parkinson's, he used to call it the 'shaking palsy', 'shaking palsy' he called it...'

Rory (48/46),^e reflecting on his 'tag', shows how hard he, too, must work in order to negotiate the personal and cultural meanings associated with a diagnosis of Parkinson's and, as he speaks, he lays bare the process by which 'multiple voices find expression within any single voice' (Frank 2012, p.35).

'I don't find it (the name Parkinson's) at all helpful.' **J: No** 'It isn't helpful in any way at all. **J: No** 'It's got a shocking image with it. Several forums I've looked at have sort of said, you know, we need to find a better name for this, for somebody who's young, who has the same condition, because the sort of progress and the way the disease works is kind of different or can be, or the course of the illness may be slightly different from if you're 70 when you're diagnosed, you know.'

For both Rory and Sarah, there is considerable tension between the 'external' story of Parkinson's – still shaped by its nineteenth century nosology - and the way in which they wish to narrate their own experience. Zoe, too, drawing on contemporary arguments,¹³ rejects the possessive form of eponym used to describe

^e Numbers in brackets refer to Rory's age at time of interview followed by age at diagnosis.

her condition; she also questions the use of the word disease as a descriptor, and touches on the individual nature of the illness:

‘It’s not Parkinson’s disease, it’s mine and it’s not a disease because it’s not contagious, so why do they call it Parkinson’s disease?...it’s my condition ...it’s a condition that I have that’s similar to other people’s, but not the same.’

I ask Rory what he would choose instead, to which he responds:

‘I have no idea, no idea. I’m not going back to the shaking palsy. I don’t know, because you see I don’t have a tremor, or very rarely do I have a tremor, slight maybe, but not much. So it’s mainly the stiffness, the loss of control. I mean when I’m talking to somebody about it, I say I suffer bradykinesia, which is an easy term to say because it carries no connotations with it. It’s when you say it’s an early indicator of Parkinson’s that people get jumpy, you know, it’s, it’s one of those.... It’s not a particularly helpful term, Parkinson’s. As I say, I can’t see them changing that.’

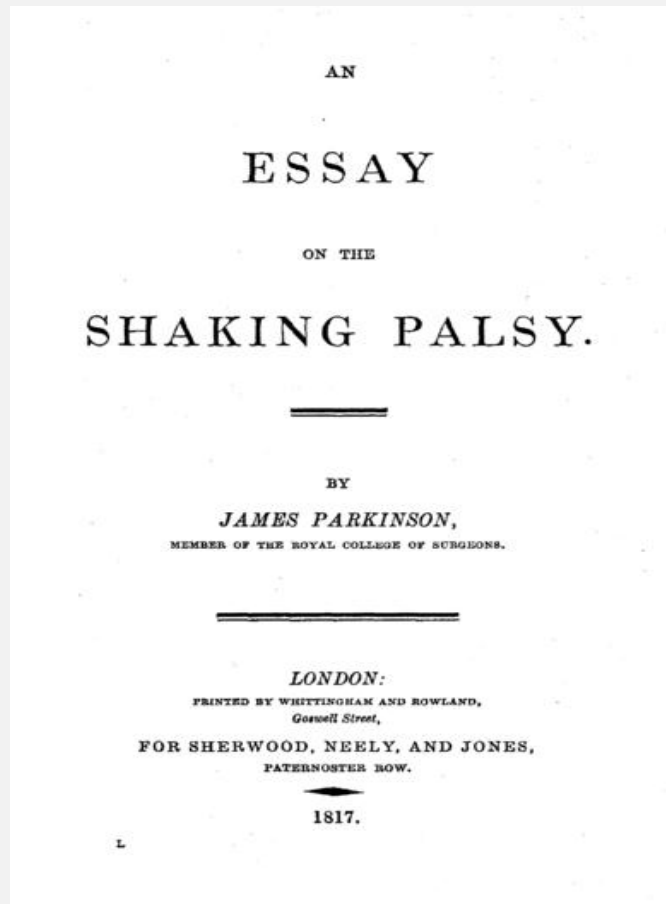
4.6.3 ‘They don’t seem to have got any further’

For Sarah, still to reference the man and his Essay in 21st century medical schools tacitly implies a dearth of progress in the intervening centuries – both in the understanding and treatment of the condition. Rather like Toombs, who is plunged into despair by (unwittingly) reading a definition of MS in an ‘outdated edition of an encyclopaedia,’¹⁴ Sarah is plunged into a state of anxiety as she describes the continued use of what she deems to be an outdated Essay. She explains:

‘...and the thing that frightens me more than anything else is the fact that students of neurology today, when they first get introduced to Parkinson’s they’re given this essay by James Parkinson, and I thought why? 1896 or whatever it was, it frightens me, it’s a 100 years old paper and they’re still reading it now. They should be reading what you’ve written today. Oh gracious me...’ She continues: ‘Well the fact that it’s 100 years ago¹⁵ and they’re still using that as a basis of the training, and I think surely they could have moved on to a more updated version of his work by now, but they don’t seem to have got any further. And all the drugs have side effects and there’s nothing straightforward about it.’

Hearing Sarah's anxiety about James Parkinson's Essay prompted me to read it without first consulting any present day accounts, reviews or analyses. Having done so, I have placed my own reflections in dialogue with others' interpretations, as outlined in Figure 5 below:

'Stories do not cease to perform when they are not being told [...] They remain resonant even when they are not consciously remembered [...] Stories are held deep in the memory.'
(Arthur Frank, *Letting Stories Breathe*, p.40)



As someone who neither has Parkinson's, nor any medical training, I found 'An Essay on the Shaking Palsy' to be a surprisingly moving description of the disease, not least because James Parkinson kept what he called 'the unhappy sufferer' at the centre of his essay. He appeared unafraid of gently chiding the medical establishment for a protracted disinterest in a disease which is 'of a nature highly afflictive,' and which leaves the sufferer with little hope other than to consider the shaking palsy 'an evil, from the domination of which he had no prospect of escape' (Parkinson 2002). The humanity of his approach is further exemplified by his suggestion that even though he may be censured for an essay based on observation

and conjecture alone - as opposed to anatomical certainty¹⁶ - he would feel himself fully rewarded if he managed to ‘excite the attention of those, who may point out the most appropriate means of relieving a tedious and most distressing malady’ (ibid). He continued with what has become an enduring and oft-quoted description of the condition:

Involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forwards, and to pass from a walking to a running pace: the senses and intellects being un-injured.

Although Parkinson did not describe every feature of what is today recognised as Parkinson’s disease, his definition is still one that is recognised by neurologists in the 21st century, referring to a combination of: tremor while at rest, lessened muscular power, abnormal truncal posture, and festinant propulsive gait.¹⁷ He also described the pattern of progression;¹⁸ some of the ways that it affects daily functioning, such as writing and feeding; the loss of automatic motor function; the impairment of speech and swallowing and, ultimately, the utter debility of a disease for which there was no treatment at that time (Kempster, Hurwitz et al. 2007). The following extract leaves one in no doubt that he was profoundly moved by what he had observed in the six ‘cases’ described in his Essay: “*As the debility increases and the influence of the will over the muscles fades away, the tremulous agitation becomes more vehement. It now seldom leaves him for a moment; but even when exhausted nature seizes a small portion of sleep, the motion becomes so violent as not only to shake the bed-hangings, but even the floor and sashes of the room. The chin is now almost immoveably bent down upon the sternum. The slops with which he is attempted to be fed, with the saliva, are continually trickling from the mouth. The power of articulation is lost. The urine and faeces are passed involuntarily; and at the last, constant sleepiness, with slight delirium, and other marks of extreme exhaustion, announce the wished-for release*” (2002, p. 225).

It is understandable that someone diagnosed with Parkinson’s – even at a time when treatment is now available – might find this description hard to bear, however humane the author’s intentions. Ivan Vaughan - who decided not to rely solely on

drugs, but rather experiment with his usage of Levodopa, thereby experiencing the condition much as the ‘cases’ described above - stated simply that James Parkinson’s description was “*accurate and daunting*” (1986, p.30).

I have found that my own reaction to James Parkinson the man - through the reading of his *Essay* - is supported in recent papers published about his life and work. He is characterised as a compassionate and caring physician whose modesty and humility would have resulted in embarrassment at having the condition named after him (Calne 2002, Lees 2007). He was very much a product of the Enlightenment,¹⁹ showing a keen interest not only in medicine, but also palaeontology, chemistry, geology and issues of social reform. Although his name was given to the disease posthumously, a gastropod, ammonite and fern were named after him during his lifetime (Goetz 2011, Lewis 2012).

When Parkinson wrote his *Essay*, the study of neurology was in its infancy and diseases such as Alzheimer’s, Multiple Sclerosis (MS) or Motor Neurone Disease (MND) - reported on so regularly in our contemporary media - had yet to be classified (Lewis 2012). It was Jean Charcot, the French neurologist,²⁰ who was the first to describe MS and MND/ALS as separate diseases. He also broadened Parkinson’s description of the shaking palsy by noting bradykinesia (slowness of movement) as one of the four ‘cardinal’ symptoms of the condition, the others being tremor (at rest), rigidity and postural instability. Indeed, it was Charcot and his



Drawing by Jean-Martin Charcot of a Parkinson's disease patient in Morocco, 1889

students who recognised the spectrum of the disease – that it could be tremorous or akinetic (rigid) and that it could entail arthritic changes, autonomic dysfunction as well as considerable pain (Goetz 2011). Charcot’s recognition that people with this condition were neither necessarily weak nor tremulous led to his rejecting the term ‘shaking palsy’ in favour of ‘La Maladie Parkinson’ and thus it became known as Parkinson’s disease more than 50 years after James Parkinson’s death (Calne 2002, Lees 2007, Goetz 2011, Casner 2012)

Figure 5 Reflections on Parkinson's *Essay*

Sarah's disquiet has stayed with me throughout my research and although it is not within my power to alleviate her anxiety, I wish to acknowledge the importance of her voice in guiding this chapter. Listening again to Sarah's disappointment as she tells me *'they don't seem to have got any further,'* I am transported back to the writings of the intrepid American photographer Margaret Bourke; back to a time fifty years previously when 'the use of levodopa had not been discovered; the workings of the brain were not well understood; there were no medications; deep brain stimulation had not been developed; and the use of various therapies was rudimentary and consisted mostly of physical therapy in the form of massages.'²¹ Musing on the name and understanding of her malady she wrote:

The disease's odd name comes from Dr. James Parkinson, a palaeontologist as well as a practising physician. In 1817, he published his observations of six victims of the disease, noting each weird and ugly symptom. This chronicle has become a medical classic, and yet in the 128 years from Dr. Parkinson's death to the onset of my own siege little more had been learned (Bourke-White 1963, p.363).

I am struck by the resonance between these two women's voices whilst at the same time acknowledging an important - albeit not *'straightforward'* - difference: the development, in the intervening years, of a drug therapy with which to treat Parkinson's.²²

Despite this crucial difference, as long as Parkinson's remains the eponymous name²³ for their disease, participants' illness stories will continue - wittingly or unwittingly - to be shaped by the man and, of course, his Essay. It is also clear that James Parkinson and his Essay will continue to exert considerable sway over neurological practice, both as a reference point for understanding and measuring 'progress', as well as revealing 'unresolved issues' of the present and future (Lees 2007, Goetz 2011).²⁴

4.7 'A bit of tremor in elderly folks'

As already mentioned the 'individual' nature of Parkinson's resonates in many participants' stories. Also resonant in most participants' stories – but greeted with considerably more ambivalence - is the perception that Parkinson's is a disease of the elderly involving little more than some shaking. Indeed, over ten years ago

Calne²⁵ drew attention to surveys in the United States which suggested that, whilst most people had heard of Parkinson's disease, many thought it to be a "relatively trivial disorder, the cause of a bit of tremor in elderly folks"(Calne 2002). Ten years later the situation appears not dissimilar in Britain, with Parkinson's UK²⁶ launching an advertising campaign in December 2012 to raise awareness of the challenges faced by people with Parkinson's because "shockingly, a recent poll showed that three quarters of people in Britain (77%) [have] little or no knowledge at all about Parkinson's" (PUK 2012/13).

Charles, in his early eighties, says 'I think I was talking to somebody [...] a couple of years ago, and I mentioned I had Parkinson's and they moved away from me – I thought to myself he thinks I'm contagious or infectious or something [...] So I think that was quite evident, you know, based on some kind of fantasy he had – I think he had a fantasy about it, that he would get it. Umm. I think people are more aware than they were, but I don't think they're entirely sure what it's all about really [...] I think most people have some idea of Parkinson's (reflective)... but I don't think they know what the experience of it can be like.²⁷ On the other hand, some people have had relatives who've had Parkinson's, of course, and are very understanding [...] Sometimes they get a worse picture of my illness because of what they've suffered or what they've seen as the suffering of their own parent or whatever.' He continues a little later: 'There are people who, where a Parkinson's patient fell down, think of them as being drunk – that's a classic thing they say, you know.... people being taken off to police stations because they've been deemed to be drunk^f and they're in fact suffering from Parkinson's. So I think there's still quite a lot of ignorance about it.'

Of course, every person now living with a diagnosis of Parkinson's was once free of that 'tag.' Thus, not surprisingly, many of my participants – like the majority of British people in the PUK poll – were formerly unaware of the challenges associated with such a diagnosis. In many of their stories, I hear astonishment as they reflect that there was once a time when they, too, thought Parkinson's was little more than 'elderly folks' suffering from a 'bit of tremor.'

^f Appendix 9 provides actual examples from my participants' experience.

Zoe, diagnosed in her late twenties, states simply: ‘I didn’t have a clue what Parkinson’s was, I had no idea at all. I just thought it was old people shaking – because that’s immediately what – well, you ask anybody without prior knowledge of Parkinson’s: It’s old people shaking.... and that’s it. Nothing else, it’s just old people shaking.’

Similarly, **Pat**, in her seventies, explains that for most of her life ‘like everybody else, I thought Parkinson’s was just sort of shaking about.’ However, she gained a little more insight shortly before her own diagnosis when she made contact with a friend whom she had not seen for a number of years: ‘I thought I’d just call in, and Oh God, when I saw her, because you think Parkinson’s is just a shaking arm, she was like one of those grafts you see when they’ve taken the skin off. Her veins were standing out. She was absolutely ... arms like this really’ (she shows me arms flailing in the air)...

Janet also claims that, when diagnosed in her mid-forties, she knew ‘nothing really. I knew that Parkinson’s, you know, because of the shakes, but not Parkinson’s of muscles and the rigid form. I knew about the shakes because my mother in law has the shakes.’

This notion of its being a disease of the elderly is so deeply embedded in the Parkinson’s ‘master narrative’ that even prior knowledge to the contrary does not truly affect Darren and Rory’s perception when faced with their own symptoms:

Darren, diagnosed in his forties, starts by saying that: ‘My knowledge of Parkinson’s was zero. I, like most people, thought that it was an old person’s disease’. He follows this immediately with: ‘You probably get sick of this, I knew about Michael J. Fox.’²⁸ Realising that he therefore did know something, not zero, he explains: ‘I obviously knew younger people could get it, but I felt it was very rare for young people to get it.’

Rory, also diagnosed in his forties, explains that because of his love of the film Dr Hollywood, he knew Michael J. Fox had Parkinson’s. Beyond that, he knew very little because, ‘You don’t need to know a lot, right, you haven’t got it. It’s that simple.’ And even when he found himself faced with ‘googling’ inexplicable symptoms, he ‘discounted Parkinson’s as [I was] far too young.’

Rory's view that one knows little about a disease unless personally affected by it is echoed by Jay, who also reflects on what 'elderly' means in contemporary society:

'I mean I am surprised by the number of people who suffer from it. Some are quite young. I didn't realise that until I started reading, which you don't, do you? It affects somebody else, not you (echoes of Rory). You tend to take your health for granted. [It's] Not until you're affected by it that you realise that you shouldn't be taking it for granted [...] It mainly affects the elderly [...] Of course it does affect some young people. So it's, I suppose, classified as an old people's illness, which in my case it wasn't, you know, you don't classify 55 or whatever, 53 as – I don't think of myself as old, I still don't. You don't really, do you?'

4.7.1 'You're not old and you don't shake!'

According to Frank, just as stories about 'categories' of people can injure them, so too 'silences can be [...] injurious' (2010, p.75). For Oliver it is clear that a Parkinson's narrative telling of 'a bit of tremor in elderly folks' bursts with 'injurious silences;' silences that may have a negative impact not only in understanding "What does this illness mean for me now and in the future?" but, as importantly, "What does this illness mean for me in my relation with others?" (Toombs 1995a). In reply to my asking what he knew about Parkinson's prior to diagnosis he explains:

'Bugger all to be honest with you. I had no, I mean I knew of it, and my headmaster, old headmaster, didn't die of it, but had it. And so I was aware of what it was and what it did, kind of. But I was pretty much the same as most people are when I tell them – the common response is that **'You're not old and you don't shake.'** And therefore it's almost as if they're saying, **'You haven't really got it, have you?'** But, you know, you just explain to them that actually there are other things, **there are other symptoms**, other things that it causes and other things that it does, plus I was starting to get a tremor now anyway, so that is making life easier in that respect! Though it only manifests at certain times. But it's, yes my knowledge was really quite poor.'

Any perception of Parkinson's as a 'trivial disorder' is surely dispelled when, in stark terms, Oliver describes himself as *'broken'*. I remember now how unbearable

it felt to sit across from someone younger than me and hear him describe himself in these terms. As I listen again to this part of the interview, I hear my discomfort in my questions:

[Talking about his former wife]... ‘She didn’t want to be with a broken person. So that’s... **J: Is that how you view yourself?** Well I am. **J: Do you think you are?** I know I am. **J: Right.** I can’t do the stuff I should really be able to do at 44 especially for somebody of my physical fitness. The part of my brain is dead and continuing to die. There’s no other way to view it other than that. I mean yes it’s, in many ways it’s affecting me the same as getting old, except for the fact I’m not old. There are times when I move like a 60 year old, and I really should not. You know I really should not, it’s just crazy.’

4.7.2 Pathophysiology: ‘Part of my brain is dead and continuing to die’

Loss of dopamine is, of course, the reason for Oliver stating, bluntly, that his brain is ‘*dead and continuing to die.*’ This process is central to the Parkinson’s disease narrative, although most participants prefer to describe it in less blunt terms, instead deferring to statistics. Kay states simply:

‘They say about 80% of the cells, dopamine making cells, die by the time you get diagnosed.’

In strikingly similar words, Adam comments:

‘They reckon that by the time you're diagnosed with Parkinson's, 80 per cent of the dopamine producing cells have already gone. Is that what you've heard?’

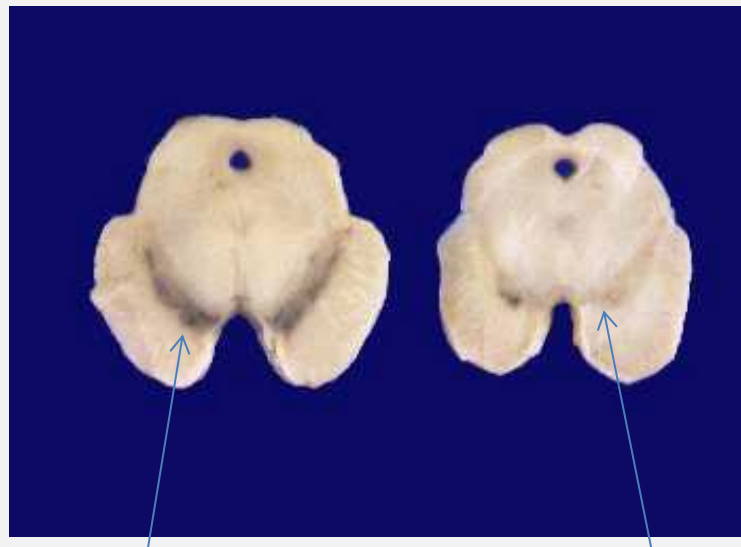
Not wishing to disrupt the flow of the interview, but expected to reply, I simply state: ‘I think that's what I've heard too, yes.’

The fact that Adam, Kay, and other participants are able to speak not only about a loss of dopamine producing cells, but also talk in terms of the percentage²⁹ of cells lost by the time of diagnosis, is a reminder that - despite Sarah’s anxiety that ‘*they don’t seem to have got any further*’ - participants’ current illness experience is rooted in, and shaped by, an evolving story of progress and discovery.³⁰

THE CONTEMPORARY STORY

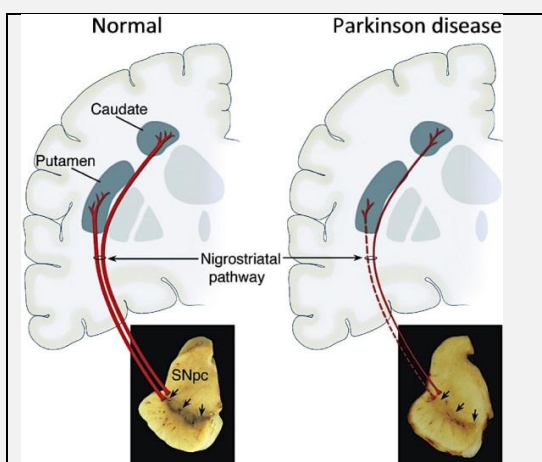
‘Parkinson’s disease is a common progressive bradykinetic disorder that [...] is characterised by the presence of severe pars-compacta nigral-cell loss, and accumulation of aggregated α -synuclein in specific brainstem, spinal cord, and cortical regions. The main known risk factor is age. Susceptibility genes including α -synuclein, leucine rich repeat kinase 2 (LRRK-2), and glucocerebrosidase (GBA) have shown that genetic predisposition is another important causal factor.

Dopamine replacement therapy considerably reduces motor handicap, and effective treatment of associated depression, pain, constipation, and nocturnal difficulties can improve quality of life. Embryonic stem cells and gene therapy are promising research therapeutic approaches’ (Lees, Hardy et al. 2009).

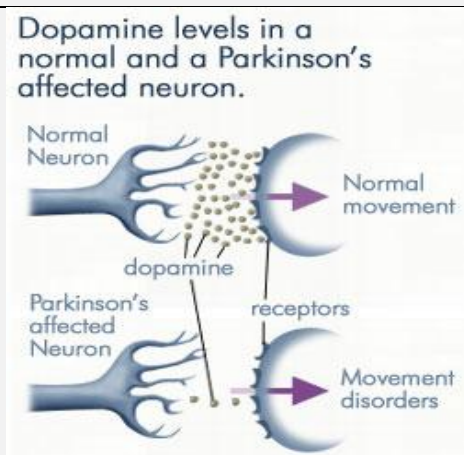


Substantia nigra of a person without Parkinson’s

Substantia nigra of a person with Parkinson’s



31



32

HOW THE CONTEMPORARY STORY CAME ABOUT
(The story behind the story)

It was in the 1890s that the French neurologist, Brissaud,³³ first suggested that damage to the substantia nigra (literally the ‘black substance’) may be a key factor in Parkinson’s. This was followed, in 1919, by Tretiakoff’s³⁴ examination of the substantia nigra of nine Parkinson’s patients, which confirmed damage in this area (Stern and Lees 1990, Lees, Selikhova et al. 2008). It was not until the 1950s, however, that dopamine - a neurotransmitter or chemical messenger - was found to be present in the human brain, at which point a group of Swedish scientists demonstrated “*a pathway between dopamine-containing cells in the substantia nigra and cells in the striped body (corpus striatum) of the basal ganglia*” (Stern and Lees 1990). The Nobel prize winning Arvid Carlsson,³⁵ through experiments with the Indian drug reserpine, showed that dopamine played a crucial role in motor control (Stern and Lees 1990, Butcher 2000) and it was shortly thereafter, in Vienna, that Oleh Hornykiewicz³⁶ discovered a lack of dopamine in the brains of people who had died from Parkinson’s (Hornykiewicz 2002, Goetz 2011). The discovery in 1961 that injected levodopa improved akinesia in people with Parkinson’s led to the development of levodopa in oral form by the end of the decade (Jankovic 2008). Today, it is generally agreed that damage to dopaminergic neurons in the substantia nigra affects the operation of the striatum – a key structure involved in motor co-ordination. A lack of dopamine prevents nerve cells functioning properly, disrupting the successful transmission of messages and triggering Parkinsonian symptoms. However, the reason for dopamine depletion is still an unknown, recalling Brissaud’s remark over 100 years ago that ‘Parkinson’s disease remains so utterly inexplicable that we are constantly drawn to it by the lure of the mysterious’³⁷ (Stern and Lees 1990, p.21).

Figure 6 The contemporary story

It is with fascination that I hear this view from over a hundred years ago perpetuated in Richard's narrative. Diagnosed with Parkinson's for under a year, he tells me:

'It's just fascinating in medical, scientific, biological terms as to what causes this disease. I mean **there's so much of a mystery about Parkinson's**, and there's no single gene like cystic fibrosis or something like that, it's going to be no simple answer to this and... unless somebody weaves some magic... It, it would be wonderful to think that all of this effort that's going into it.... someone, somewhere... is going to come up with a rational, simple explanation - I don't believe it, but it, it's nice to think that that might be the case. It probably won't be, but the avenues of research that are being pursued are all evidently quite fascinating in biological terms, in their own right.'

4.7.3 'I'm one of the fortunate ones'

The mysterious nature of Parkinson's is reflected not only in its unknown aetiology^g but also in the external narrative reassembled by participants as they speak of Parkinson's 'creeping up' on them (discussed in chapter 5). Even once it has 'crept up' on them there is no certain diagnostic test to establish what 'it' is. As Barbara explains:

'If anything surprised me, perhaps it's the fact that there are no, as yet, no definitive ways of diagnosing Parkinson's.'

'PD is diagnosed on clinical criteria; there is no definitive test for diagnosis. Historically, pathological confirmation of the hallmark Lewy body on autopsy has been considered the criterion standard for diagnosis. In clinical practice, diagnosis is typically based on the presence of a combination of cardinal motor features, associated and exclusionary symptoms, and response to levodopa. Although the diagnosis of PD is straightforward when patients have a classical presentation, differentiating PD from other forms of parkinsonism can be challenging early in the course of the disease, when signs and symptoms overlap with other syndromes' (Jankovic 2008, pp.373-4)

^g See Appendix 11

Given the difficulties inherent in diagnosing Parkinson's, it is perhaps not surprising that tests to rule out a number of other conditions have become part of the external disease narrative. Such a process leads to participants having to understand that the medical profession operates within a 'hierarchical ordering of conditions'³⁸ (Pinder 1992a, p.8) which, in turn, feeds back into participants' narratives as they learn that they do not have a 'fatal' disease. The following excerpt from Zoe's narrative shows some of the tests that may be involved, at the same time illustrating how subtly – and possibly inadvertently - pressure may be exerted on a patient to be 'grateful' for their diagnosis:

'They sent me for a nerve conduction study, where they put electrodes on your skin and they 'up' the electricity and send volts through your arm and you get the kind of clenching, horrible clenching feeling. They were inconclusive. So then they said well, *'we need to send you for an MRI scan because we think you might have a brain tumour,'* umm, and so the results came back, umm, with no brain tumour, so **I'm one of the fortunate ones**, you know, that haven't got a brain tumour. But then it could be Wilson's disease –it's when there's too much copper in the body... and it manifests itself in the same symptoms as Parkinson's...but it shows itself as, umm, I think it's copper rings around the eyes. The ophthalmologist said *'You'll be pleased to know you haven't got Wilson's disease'* so at this point I was, like, well, 'Ok, that's great, I'm not going to die'...' cos Wilson's disease can be fatal, umm....'

In an aside, hear echoes of Zoe's story in the script of the film 'Love and Other Drugs':

A 26 year old with Young Onset Parkinson's (played by Anne Hathaway) turns up at a hospital in need of medication after her drugs have been stolen in a burglary. After she has reeled off an impressive list of drugs, dosages and quantities required the doctor comments: *'So, Early Onset Parkinson's? That's rare,'* to which she responds: *'Yeah, yeah. First they thought it was essential tremor.'³⁹ Then Wilson's disease. Then Huntington's.'⁴⁰ Then they tested for MSA, PSP, Syphilis – I was very glad for a negative on that one [...]. Let's see, then there was brain tumour week – which was very scary...and 6 months chasing obscure dystonias – but now it just turned out to be good, old-fashioned Parkinson's.'*

Table 6 Excerpt from the Hollywood film 'Love and Other Drugs (2010)

4.7.4 ‘Good, old-fashioned Parkinson’s’ - ‘Will it kill me?’

It is, of course, diagnosis that brings the external disease narrative undeniably into the foreground. Participants are forced to abandon their ‘*vague knowledge*’⁴¹ of Parkinson’s and start to inhabit a world in which their predicament is made explicit by exposure to a new vocabulary. The latter consists of words that, as Keith says, ‘*you don’t really want to hear*’ when they apply to you; words that include ‘neurological,’ ‘progressive,’ ‘degenerative,’ ‘lifelong’ and ‘incurable.’⁴² At the same time, participants are told that with Parkinson’s ‘*you die with it, not from it.*’⁴³ Some derive comfort from this adage. Others find it distressing:

Darren tells me: ‘I said to him, you know, not knowing about Parkinson’s, I said, ‘Will it kill me?’ And he said, you know, he expects me to ‘*live for 30, 40 more years.*’ And ‘*Parkinson’s won’t kill you.*’ So I was impressed he was giving me 30 or 40 more years, I was quite happy about that! I thought if I keep going for forty years, I’m quite happy.’

For **Ted** there is little comfort to be derived from what he views as the medical equivalent of smoke and mirrors: ‘The neurologist said to me ‘*the Parkinson’s won’t kill you; you’ll die with the Parkinson’s*’ but... **J: How did that make you feel?** Well, I said ‘how long do you think?’ He said ‘*You’ll go on forever*’ you know but... because he says ‘*the Parkinson’s won’t kill you but condition[s] developing while you’ve got Parkinson’s, made worse by Parkinson’s, in the end they’ll kill you.*’ You know...it’s silly ... because if you can’t, if you can’t walk, you can’t move about, you sit in a chair, you know, you don’t get no exercise, nothing, your life expectancy goes down, doesn’t it?’

Similarly, **Marianne** thinks such a view is a matter of semantics: ‘You do die of it though.’ **J: Well that’s something that has confused me.** ‘There’s elements of the condition we haven’t spoken about – the swallowing. Sometimes if I swallow, I mean just my saliva, just during the day I might cough and my saliva had gone down the wrong tube, which is a daily process, which is quite scary sometimes. And if I’m eating and swallowing food, sometimes it won’t go down my throat the way it’s supposed to go and then I will cough it up and I’m fine. But I’m sure there’s people that die all across the world in that moment where it’s gone down the wrong way and they can’t do anything about it. There’s little elements of the whole condition which actually is a disintegrating process of function.’

Richard, having recalled what Parkinson's did to his father-in-law, reigns in his fear by invoking the hierarchical ordering of conditions: 'But it's not cancer.' **J: Mmm.** 'You know it's not a traffic accident, something like that. I mean people, people's lives are thoroughly wrecked by certain accidents or diseases. Parkinson's gets like that in the end, but you're able to plan for it.'

Jonathan is clear that, actually, 'It's terminal' before immediately assuaging this bitter pill with the view that 'I mean life is finite anyway.'

Table 7 'You die with it, not from it'

Running parallel with this narrative that '*you die with it, not from it,*' is a complex external narrative related to symptoms, disease stages, drug treatments, disease genesis and – above all - the thorny issue of a cure. The remainder of this chapter will touch upon these issues.

4.8 Symptoms

4.8.1 'The external expression of disease'

Parkinson's Disease: The Quintessential Neuropsychiatric Disorder

'Although diagnosed by characteristic motor features, Parkinson's disease may be preceded, and is frequently accompanied by, a wide range of cognitive and neuropsychiatric features. In addition to the most commonly studied disorders of dementia, depression, and psychosis, other relatively common and clinically significant psychiatric complications include impulse control disorders, anxiety symptoms, disorders of sleep and wakefulness, and apathy. These problems may be under recognised and are frequently undertreated. The emergent focus on nonmotor aspects of Parkinson's disease *over the past quarter of a century* is highlighted by a nonlinear increase in the number of articles published devoted to this topic. Although the development of newer antidepressants, atypical antipsychotics, and cholinesterase inhibitors in recent years has had a positive benefit on the management of these troublesome and distressing symptoms, responses are frequently suboptimal, and this remains an area of major unmet therapeutic need' (Weintraub 2011).

Table 8 Movement disorder or neuropsychiatric disorder

Symptoms are an intriguing part of any narrative account of illness. After all, it is symptoms, 'the external expression of disease,' that lead people to seek medical

attention, and it is the ‘medical reading’ of any symptoms that leads, ultimately, to diagnosis (Jutel 2011, p.81). Since Parkinson’s is a progressive, degenerative condition, it is not surprising that, as the disease evolves, symptoms may intensify or new ones may emerge, and therefore it is ‘the symptom’ that remains central to any medical interpretation of disease progression.

The manner in which symptoms affect participants and their illness narratives will become apparent in the following two chapters. However, it is important to note here that my participants’ narratives have been told within the context of a paradigm shift. The latter is still evolving, having started a little over quarter of a century ago (see above) and it is one that aims to alter the understanding of Parkinson’s as a ‘common movement disorder’ (Casner 2012, p.657) to one that recognises the role played by non-motor symptoms both *before* the first physical symptoms manifest themselves, as well as *during* the progress of the disease.⁴⁴

This shift in understanding within the medical profession takes time. A local neurologist opened a talk I attended by saying his aim was to ‘*dispel the myth that Parkinson’s disease is benign*’ and that he needs his fellow medical professionals to understand that it is ‘*a neuropsychiatric disorder [involving] multi centric neurodegeneration*’^h This plea echoes Weintraub’s paper of 2011, and is further echoed in a more recently published paper:

‘Clinicians frequently *overlook* non-motor symptoms and *do not discuss* important symptoms like depression, anxiety, fatigue and sleep disturbance. [...] despite [the NICE] 2006 guidance (above), an international survey in 2010 showed that upto 62% of PD patients *do not declare symptoms* such as apathy, pain, sexual difficulty, bowel incontinence or sleep disorder, either through embarrassment or being unaware that their symptoms link to PD. Furthermore, clinicians themselves may not realise that these symptoms need addressing’ (Todorova, Jenner et al. 2014).

4.8.2 Participants’ views on non-motor symptoms

While reading my transcripts I have kept a ‘tally’ of each person’s symptoms in the order in which they emerged during the interview. I have included some of the symptoms 12 of my participants chose to talk to me about in the appendix. Although

^h Lecture on 31.01.14.

not exhaustive, the lists provide an indication of the vast array of symptoms any one person might experience as the disease progresses.ⁱ

There are doubtless silences in participants' narrative accounts, and yet I have found people to be very open about their experience of living with Parkinson's, including mention of some of the more 'embarrassing' non-motor symptoms mentioned above. It feels important to expand this dialogue, since it is through the many different voices that one is able to hear how a shift in narrative emphasis (from motor to non-motor symptoms) is, indeed, long overdue. The following table⁴⁵ touches on many of the symptoms that, as suggested above, clinicians either overlook or [some] people with Parkinson's fail to mention.

Barbara: 'And I think the non-motor symptoms are, some of them are most inconvenient because I obviously have this problem with anxiety [...] But principally it's the anxiety, I wonder what's going to come round the next corner. When something does, I'm fine, but it just worries me. **J: And does the Parkinson's nurse have any advice for that?** 'No, not really. No, there seems to be much less emphasis on the non-motor symptoms which is obviously now leading to quite a lot of work being put into looking at it. But it's, it is a bit of a neglected area, I think.'

Julian, having taken part in a research study 'looking at things like anxiety, depression, and sleep particularly, more than anything' tells me: 'Various aspects of the study have been published. As I recall, the gist of it is that non-motor symptoms are a major problem which, which anyone could have told them to be honest. And also that, as I recall, that the main, most dominant feature in most Parkinsonian patients lies with sleep. If you don't get enough sleep then everything else falls apart beyond that. And again pretty much anyone could have told them that.'

Following diagnosis, **Sheila** explained in vivid words that have stayed with me: 'er, this might be personal to me, I don't know, but every joint in my body, umm, feels as if it needs, feels as though I need to go on a rack, you know, be stretched really, umm, not painful but [...] incredibly uncomfortable, can't keep still, you just really need to stretch and, you know, you want someone to pull you apart sort of thing...'

Mary finds that it is by talking to others with Parkinson's rather than her consultant

ⁱ See Appendices 13 and 14.

that she finds out about non-motor symptoms: ‘And it was just nice to talk to other people because the consultant I had at the time, I had a lot of faith in him, but he was very short and matter of fact and, you know, there was never really any discussion really about, much discussion about Parkinson’s.’ Elaborating on some of the ‘annoying’ things, she mentions ‘seeing things that are not there, you know [...] I mean I usually see, it’s either people or animals that move very fast past, out of the corner of my eye. Other people seem to see other things. The fact that we don’t smell, you know, most of us have lost our sense of smell – that had never really – my consultant or GP had never discussed that at all. And it hadn’t really particularly occurred to me that it was something to do with Parkinson’s.’

Edna, speaking about her carers, says ‘So I can’t go out for an evening. **J: No, so that really has an impact on your social life, doesn’t it?** ‘And also I’ve got... pads. **J: Yes** ‘Which I hate.’ **J: I bet you do** (she pulls a face which shows how much wearing a pad distresses her). ‘It restricts me from going-I can’t go down to [...] for the day. **J:** [it is hard to hear what she has said, so I ask for clarification] **You can go to [...] for the day, or not?** ‘No I can’t, can’t.’ **J: No, no.** ‘Somebody needs to help me to go to the toilet, you’ve got to go to have your pad taken off and be hoisted and this business.’

Jonathan, talking has a new drug regime: ‘And that’s a fairly new situation. I’ve only started the...I was over Christmas, just before Christmas I had, I was bedridden, I couldn’t get out and I couldn’t go to the lavatory. I mean I couldn’t make it to the lavatory. So the medication was increased and that resolved that problem.’

Sarah, having searched for lip salve to apply to her dehydrated lips, is reminded of the difficult cycle she sometimes finds herself in: ‘It’s dehydration. That’s another thing with Parkinson’s, you’re supposed to keep hydrated [...] The more I drink, the more I have to go to the toilet and it becomes urgent. That’s the pattern, the thing with the drugs as well.’ **J: Yes. And when it’s urgent it’s urgent?** ‘I’ve got to go, I can’t wait and I’m frantic. I’ve wet myself a few times...’ **J: You poor thing.** ‘I stick the m [jeans] in the wash. A year ago it would have upset me and I’d be in tears [...] I’ve asked for a female carer first thing in the morning. They still send me men sometimes. I get so cross. But I’d rather have nobody than have a man. It’s very embarrassing isn’t it when you wet yourself ... to do it in front of a man.’

Rory, having spoken about motor symptoms lists some of the non-motor symptoms:

‘I mean, yes the confidence, constipation which I believe is common throughout. I take whatever it’s called, Movicol or whatever, and I survive. There are some sexual problems which, yes...’ (He hesitates and sighs). ‘What else do we have? Confidence, sleep, of course.’

Pat ends the interview with a ‘laugh’ and ‘awful visions’ that make ‘the mind boggle.’ [...]: ‘Well the only thing that makes me laugh, and this is totally stupid, is when it says, ‘Sex,’ not that I’m likely to get any, ‘Sex and Parkinson’s.’ I’m still wondering about that! [...] I’ve still got the folder with all the bump they gave me in it. But I saw this in the folder, ‘Sex and Parkinson’s.’ And I thought I won’t need that and afterwards I thought the mind boggles, you know [...]’ **J: Is that a note to end on?** ‘It’s a good note to end on – sex and Parkinson’s. How does it work, as it were?’

Table 9 Frequently overlooked non-motor symptoms

4.9 ‘No aspect of human reality [...] is without temporal dimension’

As a consequence of this current shift in the external disease narrative, it has been suggested that Parkinson’s be divided into a ‘preclinical phase,’ a ‘premotor phase’ followed, ultimately, by a ‘motor phase’⁴⁶ (Stern, Lang et al. 2012, Todorova, Jenner et al. 2014). At the same time, Stern et al recognize that any ‘new definition of PD will initially serve our research agenda rather than dramatically change the clinical approach to PD’ (ibid. p.56).

In the medical world the Hoehn and Yahr scale is one system⁴⁷ commonly used for describing, in broad terms, how Parkinson’s symptoms progress and the relative level of associated disability.⁴⁸ The World Health Organisation (WHO), on the other hand, describes the progression of Parkinson’s in four stages, using the broad headings: Early; Intermediate; Advanced; and End (WHO 2006).

Stage	Symptoms
Stage 0	No signs of disease
Stage 1	Symptoms on one side only (unilateral)
Stage 1.5	Symptoms unilateral and also involving the neck and spine
Stage 2	Symptoms on both sides (bilateral) but no impairment of balance
Stage 2.5	Mild bilateral symptoms with recovery when the 'pull' test is given (the doctor stands behind the person and asks them to maintain their balance when pulled backwards)
Stage 3	Balance impairment. Mild to moderate disease. Physically independent
Stage 4	Severe disability, but still able to walk or stand unassisted
Stage 5	Needing a wheelchair or bedridden unless assisted

Table 10 Hoehn & Yahr Scale

The Parkinson's nurse specialists with whom I met used a comparable four stage model, namely: Diagnostic, Maintenance, Complex and Palliative (Thomas 2004).⁴⁹ Although this descriptive model has been challenged,⁵⁰ I mention these approaches not to discuss their merits, but rather to illustrate how the external disease narrative that underlies any account of Parkinson's is interpreted medically through symptoms, as discussed, and is viewed within a temporal framework.

A Parkinson's nurse specialist put the reality of this time frame to me before I began recruitment for this study. He advised me to bear in mind the four stages he had outlined (above) and I remember my feeling of disquiet as he allocated numbers to each stage. Thus I learned that - in very broad terms - once diagnosed with Parkinson's there is a 15-20 year period when drugs will provide relief. Within this time frame, the Maintenance stage may last for 4-5 years, followed by the Complex stage of 5-10 years. On reaching the end of this stage, people are taking so many drugs - including drugs to counter other drugs - that the side effects usually become unbearable, at which point patients are moved to a palliative care regime, where drugs are reduced.^j

^j It is important to remain alert to the fact that not every person diagnosed with Parkinson's will experience every stage of this model, not least because the age at which people are diagnosed with Parkinson's can vary hugely. Similarly, the order in which symptoms develop, as well as symptom severity, will differ for each individual and the time frame given is a guide only.

Whilst my interest is, of course, in the individual rather than the general nature of the illness experience, it is important to understand that this is the model that health professionals involved in my participants' care hold in mind; it is the model taught to medical and nursing students;⁵¹ and it is the model that acts as a backdrop to individual narratives. It highlights the progressive, degenerative aspect of the Parkinson's disease narrative, thereby bringing into painful relief the elusive yet ubiquitous nature of time and the observation that 'there is no aspect of human reality that is without temporal dimension' (Brockmeier 2000, p.51).

4.10 Disease progression and treatment

4.10.1 'He was just a shell'

Feeding into participants' narratives is, of course, a gradually acquired knowledge of disease progression picked up from a variety of sources, including health professionals, websites, articles, support groups, as well as meeting - or having known - other people with the disease. Interestingly, whilst medical voices can frequently be heard in 'borrowed words and phrases' in my participants' narratives (Frank 2012, p.35), there is a silence surrounding the vocabulary used by health care professionals to describe disease stages. Ted, himself a former health worker, comes close when he says:

'Umm, I'm still able to put my clothes on, wash myself, go in and out of the bath... So still I'm not at critical stage yet.'

Rather, many participants acknowledge this temporal dimension to their disease by referencing what they know to have happened to others.

'I don't really know how I foresee the future. I just hope I don't come to the stage where I'm bedridden, which I know that's happened to lots of people. But I have really noticed that the people who combat it or fight it come off best' (Colin).

Jay, diagnosed in his fifties, is particularly fearful of developing dementia:^k

‘The thing that worries me more than anything is dementia, because my dad had that.’ **J: Oh.** ‘He’s just passed away. He had it for 6 years. And that was awful because he wasn’t the person that I knew. He was just a shell. And I thought that was awful. At least if you’ve got your personality you are, even if you’re sort of physically impaired shall we say, at least you’re still the person, aren’t you? But he wasn’t, he just didn’t have any memory.’

Even though ‘people may not *master* their fears through stories’ it is nevertheless through stories that they do ‘come to grips with’ or ‘*hold their own* against their fears’ (Frank 2010, p.81); fears, which in the case of a Parkinson’s diagnosis, are fed by ‘the prospect of increasing debility’ and a future that therefore ‘assumes an inherently problematic and threatening character’ (Toombs 1995a).

4.10.2 ‘This horrible spectre’

To illustrate this further, I turn to Oliver, Richard and Sheila:

Oliver: ‘But another thing that Parkinson’s seems to make you do and this is entirely psychological, is it makes you, it stops you from saying – or certain people it seems to stop you from saying, ‘Well I don’t know really,’ it makes you go, ‘Fuck it, I’ll do that NOW.’ And it makes you work twice as hard because you think, ‘I’ve got a lot to prove here. I’ve got a lot to prove and I’ve got to do it while I can.’

Richard’s neurologist told him ‘*if you are unlucky you’ve got a good 10 years.*’ I mean I’m 60, you know that’s 70, that’s a reasonable lifespan. ‘*If you’re unlucky you’ve got 10 years, if you’re lucky you’ve got 15 years*’ and I must admit, well I tend to push that to the back of my mind, umm [...] I mean I’m now conscious it’s going to be...time’s going to fly by and it’ll be a year. And I should have 10 years. So you know, I really need to get off my backside and, er, make the most of it, it really concentrates the mind.’ He also explains he has recently found a photo of his father in law, in the latter stages of Parkinson’s, ‘lolling about and drooling in his wheelchair and I thought ‘Fuck me,’ you know... So one and the same time it’s a very positive thing that you’ve got to do your best to live your life and make the

^k According to Consultant neurologist Romi Saha (lecture 31.01.14) it is estimated that 30% of people with Parkinson’s develop dementia within 10 years of diagnosis.

most of it, and then the other is this, this horrible spectre, which seems, and indeed is, a long way off, but it was rather sobering to be reminded of what this fucking disease does to you in the end.’

For **Sheila**, ‘It’s the knowledge that it is going to get worse, but you don’t know how quickly...so it’s very much about living life now, doing what you can.’ **J: Right.** ‘Quality of life now, but other people might, you know, take another decision, they might sort of slow right down and try and extend it, umm, I think there’s that quandary as well. But personally it’s sort of like do it now, you know, while you can, cos there’s the fear of being, well, bedridden, you know, you know being really, really immobile, umm ...’

Table 11 ‘People may not master their fears through stories, but through them they do come to grips with their fears’¹

All three express, in their own way, how Parkinson’s ‘concentrates the mind;’ all three acknowledge the importance of trying to do what they can, while they can. At the same time, the interview provides a safe space in which they can go beyond the present and confront their uncertain future, and all three openly articulate their thoughts about a time when the disease will have progressed and treatment will no longer be effective:

Oliver: ‘I will kill myself without doubt because there will become a point when I will be unable to carry on doing what I want to do or being what I want to be, and when I feel that I’m at that point then I will make – I don’t want to be out of control, I don’t want not to have control over my life. Ultimately it doesn’t matter because when you’re dead, you’re dead so it makes no sodding difference anyway.’

Richard: ‘Thinking back to my father in law, watching him eat was painful and, you know, I guess I try not to think about it but when I do I think ‘For God’s sake, if I reach that stage, shoot me, for heaven’s sake!’ And it’s interesting, er, it’s crossed my mind, I mean, how does one know when you shouldn’t be here anymore! (Wry laugh) Er, would I have the balls to kill myself? [speaks about methods] I shouldn’t make too much of this line of thought, actually, cos...But it’s true that I really do not want to reach the stage that my father in law was at.’

Sheila, speaking about the Dignitas Clinic in Switzerland,⁵² says ‘I’ve thought about that.’ **J: Have you?** ‘Oh yeah, yeah, very definitely. I mean I’ve talked to my

¹ Arthur Frank, 2010, p.81.

neuropsychologist and she's, I've got a Living Will, you know, that I haven't completed but just knowing that I've got it, it, umm, makes a big difference. Umm, it will be something I consider.'

Table 12 'I don't want to be out of control'

4.10.3 'The treatment of PD is alchemy'

'They don't seem to have got any further (since the time of James Parkinson) And all the drugs have side effects and there's nothing straightforward about it' (Sarah).
'The discoveries of dopamine as a neurotransmitter in the brain, its depletion in patients with Parkinson disease, and its replacement with levodopa therapy were major revolutionary events in the rise to *effective therapy* for patients with this disorder' (Fahn 2008).

Also feeding into - and shaping- participants' narratives, is the gradually acquired knowledge of the various drugs used to treat Parkinson's.⁵³ Not surprisingly, given the 'individual' nature of Parkinson's discussed at the beginning of the chapter, drug treatment is also prescribed according to individual need.⁵⁴ During the course of my interviews I have marvelled at the way in which drug names - and dosages - trip off the end of participants' tongues, only to realise that these once alien words - Levodopa, Dopamine Agonist, Apomorphine, Ropinirole, Madopar, Mirapexin, Stalevo, Cabergoline and Pergolide, to name but a few - have now become a part of my own lexicon.^m

I have also observed, at first hand, the extraordinary power of a tiny tablet in determining whether someone remains 'on' or 'off.' Just such an instance happened during my interview with Henry (53/67). In my field notes I wrote:

When I arrived, Henry was walking reasonably fluidly. Sitting on the sofa, he had a continual tremor in his left leg. It became apparent that he needed medication – which he finally took – when at one point he got up to get his briefcase. In order to get to where he needed to go, he actually ended up spinning around on the spot, and then gradually moved across the wooden floor in little pirouettes. The medication helped within half an hour.

^m Appendix 15

At the time, our conversation went as follows:

Henry: I think I have to go and just take a pill actually because I'm overrunning [...] I should have had the common sense to take one before you arrived.

J: How long would it normally take or does it normally take for the pill to take effect?

Henry: The pill, anything from 15 minutes to it doesn't take any effect at all. It depends upon circumstances, I think. But I'm hoping to go on to a different regime soon, because, as you can see, I can go fairly quickly from being quite mobile to being less than mobile.⁵⁵

J: Yes, yes. So do you actually freeze?

Henry: I can do, yes.

Although Sheila does not actually freeze during our interview, I find my imagination captured by the way in which she describes the 'on' and 'off' periods that characterise her experience of Parkinson's. She begins by describing her mother's impatience with her:

'At Christmas time, it's opening a present, you know, she's saying '*Come on, hurry up*' and, you just can't, you know, can't hurry up and... Sometimes, when, when she's taking a cup from me, you know, she'll sort of take it and snatch it from me cos I can't let go... quickly umm, you know, if my tablets aren't working, but when my tablets are working I can go out for a run, I can jog, I can skip, I can do you know what I want basically – not for very long, but I do get those windows ...of opportunity....'

I sense the performative power of storytelling as Sheila's voice fades only to return with a memory evoked by brief reflection. She now delivers this memory with some urgency:

'That's another thing, it's like, it's **like living, living and dying about three or four times a day**, you know, tablets, you sort of, you know sometimes you can't do anything, hardly anything, and other times when you can, you know, do go to the gym or what have you, so you know ...it's weird, really strange.'ⁿ

ⁿ For a further vivid and intense description by Sheila of the ramifications of taking Parkinson's medication, see Appendix 15.

Of course, the fact that there *are* drugs to treat Parkinson's is not something everybody knows at the outset. For Jean, acquisition of that knowledge brings with it relief but also a feeling of guilt, since she has a good friend diagnosed with MS for whom no such treatment options exist:

Jean: You know, umm, because... there's no medication (for MS) – like, I'm taking medication and hopefully it's going to keep it at, er, er, what's the word?

J: At bay?

Jean: At bay, or controlled... or whatever [...] Whereas Joyce can't take anything, you know the type she's got. I mean, she, she's, they are trying her again with some, umm, injections. But last time it really affected her, so she stopped taking them, but they want to try again.'

For Jay there is no guilt; just considerable relief:

Jay: So anyway eventually they started treatment and I immediately felt like a world had been lifted off my shoulders.

J: So what was the treatment?

Jay: Well the first one was Mirapexin which, I mean, a tiny little tablet three times a day and it just, you know, completely changed me.

J: Can you say in what way?

Jay: Well, I felt more alive; I felt I'd been going around like a zombie

4.10.4 L-dopa, the so-called gold standard for Parkinson's

On the other hand Caitlin finds that her previous knowledge leads her to anticipate more than simply the 'control' of her disease. She explains:

'The neurologist said the only option was for me to start on L-dopa, which is the so-called gold standard for Parkinson's. So I started on that. And it did help, but it wasn't the miracle cure I expected.' She clarifies that her expectation of a 'miracle cure' had been shaped by watching the film 'Awakenings' which is 'about Parkinson's induced by encephalitis and in that film [...] people were given large doses of L-dopa, they had a sort of miraculous recovery. So that's what I was sort of expecting when I started on it.'

A lack of restitution⁵⁶ (*‘although it led to some improvement, it wasn’t a miraculous cure at all’*) throws into relief the contingent nature of her illness, not only in relation to the treatments available, but also in relation to the social expectations and pressures to which the existence of treatments gives rise. Just as Oliver is put on the defensive by people not believing that he has Parkinson’s (*‘you’re not old and you don’t shake’*), so too Caitlin is put on the defensive by the mismatch between her experience of living with Parkinson’s and what is written or spoken about it. In her words I hear echoes of Arthur Frank’s observation that ‘when adult bodies lose control, they are expected to attempt to regain it if possible, and if not then at least conceal the loss as effectively as possible’ (1995, 2013, p.31).

‘So although people say Parkinson’s can be controlled in quite a sort of flippant way, I think the drugs, even at an early stage, can be limited in what they do.’

The reality, for Caitlin, though is far from ‘flippant’ – it is a life on benefits:

‘I mean I’ve not been in paid work for, well since [diagnosis] actually. And I’ve never felt that the drugs have improved my condition to the extent that I have felt I would be able to return to work, not paid work anyway. I do a fair amount of volunteering.’

This mismatch experienced by Caitlin extends beyond the need to point out the limitations of the drugs prescribed to ‘control’ her condition. She also finds it necessary to contest the view that she can be cured through Deep Brain Stimulation.^o From her perspective, this is the result of misrepresentation in the press:

‘Well Parkinson’s research I would have enough knowledge to know about it, although I do find that with, I think with new, not with drugs so much but with the deep brain stimulation, for example, that’s – you often read articles about that in local newspapers and so on which will put it forward, which will tell the story of one person, and will put it forward as, you know, in a way that let’s – gets people who don’t know much about Parkinson’s to think that it’s a new treatment and **it’s portrayed as a complete cure for this person.**’

^o Please see Appendix 16 for participants’ views towards Deep Brain Stimulation (DBS). DBS is also discussed further in Keith’s narrative, Chapter 6.

Such is the ‘narrative force of restitution’ that these ‘good news’ stories are seized by others to offer hope and a ‘way forward’ (Nettleton 2006, p.1173). The severity of her disease remains unrecognised as Caitlin is left to combat this perception of her disease as ‘curable.’ I sense an underlying suffering in her narrative as she tells me:

‘And I’ve had people come to me and said, ‘*You know, there’s this wonderful new surgery available, you could have it and be completely cured,*’ and I have to say, ‘Well, you know, it’s not quite like that. You know, like the drugs, it wears off after a period of time and it can have serious side effects and so on.’

4.11 CODA

4.11.1 ‘We are yet to find a cure for this devastating condition’

‘I think James Parkinson would marvel at the progress that has been made in diagnosing, understanding, and treating the condition that now bears his name. But I’m sure he’d be surprised and disappointed to discover that, almost two centuries after his essay, we are yet to find a cure for this devastating condition’⁵⁷ (Lewis 2012, p.186).

The purpose of this chapter has been to expose and work with the many elements of the ‘master narrative’ in which participants’ stories are crafted and enacted, placing the different voices into dialogue with each other. Any account can never be exhaustive, but this chapter cannot end without reference to medical research and the role it plays within the ‘master narrative.’

As mentioned above, participants’ illness experience is rooted in, and shaped by, an evolving story of progress and discovery and, whether they like it or not, their experience of Parkinson’s comes at a time when:

‘The field of neurology is rapidly changing all the time. Neurologists used to be just diagnostic clinicians but now it is a therapeutic specialisation. This is the era of neurology and *the brain is the Holy Grail of medical research*’ (Professor Tim Lynch).⁵⁸

The advent of the internet means that many of my participants have been advised (by health professionals) to seek out information and support through websites and/or local support groups. Through examining the websites of Parkinson's charities, as well as the information distributed at support groups, it is possible to glean an understanding of the social and medical context in which participants must negotiate their illness. It is a context that continues to hold the quest for a cure as its telos, as reflected in the strapline used by Parkinson's UK: 'Change Attitudes. Find a Cure. Join Us.'⁵⁹ Another rapidly growing and influential charity in the UK, founded in 2005 by four people with Parkinson's, is even more direct in its approach to research, stating that it 'is solely dedicated to finding a cure for Parkinson's.' Its chosen name is 'The Cure Parkinson's Trust.'⁶⁰

Even when exercising caution that there is 'no quick fix,' I realise that the words 'significant advances' and 'tantalisingly close to finding a cure' linger in my mind after reading the following passage:

There are numerous studies being undertaken throughout the globe relating to Parkinson's disease, its causes and effects. Most large pharmaceutical companies are also developing new drugs and participating in drugs trials. Unfortunately there is no quick fix and while there have been significant advances in the knowledge that we have about the brain and many feel we are tantalisingly close to finding a cure, drug management of Parkinson's seems to be the best option available.
(Dublin Neurological Institute Parkinson's Disease Research Appeal! December 2014)⁶¹

4.11.2 'Stories do things; they act'

(Frank, 2010, p.40)

Reflecting an awareness of this over-arching research agenda, my participants' voices are almost unanimous in framing their talk of medical research in the context of a search for a cure – the essence and emphasis of the restitution story. Whilst nobody states overtly that this research should *not* be undertaken, suggesting that a 'commitment to the idea of a cure deserves to be honoured' (Frank 1998, p.201), it is nevertheless striking that nearly all participants state that there will be no cure within their lifetime. Voicing this out loud clearly comes at a cost, visibly illustrating Frank's observation that 'stories embody deep emotion' (1997a, p.42).

To speak about medical research, particularly with reference to a cure, demands that my participants think about - and face - their uncertain future. For some, it elicits a sense of false hope; for others, the realisation that they simply want to say on an 'even keel' for as long as possible. A common reaction is to defy the future by focusing on the present.⁶²

I have found the variety of views and emotions raised by discussion of medical research range widely, from a degree of optimism and hope for the future fuelled by intellectual curiosity, fascination, and engagement in the scientific process; to feelings of ambivalence; disengagement; resignation; cynicism; fear; profound loss; isolation; despair; and even outright anger. To conclude this chapter, I wish to bring Oliver's voice further into the foreground, for it is through his reaction to medical and societal attitudes that one can hear both the performative power of stories, as well as how deeply they embody emotion.

4.11.3 'You do get a lot of people who want to cure you'

As previously mentioned, a diagnosis of Parkinson's disease results in participants having to address 'again and again' the question of what it will mean in their 'relation with others' (Toombs 1995a). Of course, 'relation with others' encompasses many possibilities, ranging from close family and friends, to neighbours, colleagues, health professionals, fellow Parkinson's sufferers and members of the public. As people tell me their stories, I, too become the 'other' for that brief period of their lives.

Rather as Caitlin finds herself in precarious opposition to others when they express the view that there is a '*wonderful new surgery*' that will cure her, Oliver finds himself similarly placed when others tell him that stem cells will cure him. His exasperation is clear:

'People say, '*Oh, but you know, the stem cells will come along and cure you,*' and it's like, 'Well, you know what, I'll be dead before it will be licensed.' So it doesn't happen overnight and they haven't actually worked out how it works yet, therefore even if it happens within the next five years, it's going to take another 15 to get licensed by which time it's just too fucking late. So that's just stupid.'

For Oliver, to have people tell him that he will be cured is more about them than him.

‘And it’s just weird; people will just latch on to the most astonishing things because they want to believe them. This is the problem. It’s the desire to believe something rather than actually looking at something from an evidential standpoint.’

Not to participate in a narrative that assumes cure and recovery opens the floodgates for examining fear and uncertainty (Gardner 2009, p.342)⁶³ and this is something that he finds others are unwilling to confront:

‘It’s just like it’s what people say because they don’t know what to say. It’s the kind of, *‘I’ll just say that they’ll be able to cure it and it will be fine and then we can sweep it under the carpet and not worry about it anymore.’*

He is similarly incensed by people who *‘talk about fighting Parkinson’s.’* To be told that he will ‘fight’ his disease or that he will be ‘cured’ is to deny him his voice. It does not allow him ‘to get to grips’⁶⁴ with his situation:

‘And people, people say this to me, you know, *‘We know that you’re going to fight this all the way,’* and it’s like, ‘Why, why, how can you fight something that doesn’t play by your rules, doesn’t understand rules, it doesn’t really give a toss, it isn’t an entity, you can’t, it’s just ridiculous! It’s a really stupid way to base your kind of modus operandi in life, I think. It’s really odd.’

At the same time, when he does voice his views in an ‘anonymous’ dialogue about curability vs. incurability over the internet, he opens himself to verbal attack:

‘There’s one guy on the internet who put up his website and he was writing all this stuff about this and *‘you can cure it like this’* and I just wrote saying it was very interesting [...] And I just wrote a little thing saying, you know, ‘One thing that you maybe need to accept here is that this is incurable, this is it, I know this, I have it.’ And he said, *‘Well, you know, you get the diseases you deserve.’*

Although others may be well-intentioned in suggesting that a cure will be found during his lifetime, the brutal reality for Oliver is that, rather than allay his fears, discussion of a cure lays bare the uncertainty of his future:

‘But there’s this, part of it is just the simple logistics of it. I mean if they, there was some huge breakthrough and they realised that it absolutely worked, it would still take too much time for me because I’d be 60 by the time I could actually use it, at which point I’d be fucked completely, I suspect. Of course you don’t know, but I sort of think that’s the case.’

The reality of these ‘simple logistics’ is echoed by many other participants, including Caitlin:

‘I think, I mean Parkinson’s UK are sort of talking about a cure within five years. I think that’s probably unrealistic. I also feel that even if a cure was found by Parkinson’s, it wouldn’t mean that life for people who had had Parkinson’s was all **hunky dory**. I mean [...] you know, you don’t read very much about the secondary conditions associated with Parkinson’s. So, for me, for example, I’ve now got quite pronounced curvature of the spine. Now if, and that causes problems with a lot of muscular pain [...] So, you know, you wouldn’t be physically okay straightaway, well for a lot of us we wouldn’t be physically okay, we’d still be left with residual physical problems that could be quite, quite limiting.’

As I listened to Caitlin, I remember wishing that she could meet Charles, whom I had interviewed five months earlier:

‘Well I’m all for, of course, all for research. I’m all for the possibility and the hope that there would be a cure, but I think I’ve always, because of having to adopt maybe a more philosophical, theological, spiritual...er holistic approach to things, er I’ve always felt that cure doesn’t necessarily mean that everything is **fine and dandy**; that people still have to reckon with their brokenness, their fragmentedness, their shadow side, and....that, er... ultimately we’re all looking for healing, wholeness.’

Importantly, Caitlin highlights the overall context in which this search for a cure is taking place and, given her own experience it is not surprising that she is fearful of the political and social implications surrounding the search for a cure:

‘And there would be the problems of having to, well we’re all being hit by benefits cuts anyway, but if we were cured of Parkinson’s, we would then be expected to go out and find work, and if you’ve been out of work for ten years, that’s going to be very hard as well. So I don’t think this talk of a cure is all that it’s cracked up to be, to be honest.’

Above all, as participants give voice to their views about medical research and the search for a cure, the existential implications are palpable. I leave the final words of this chapter to Oliver:

‘Well, there’s nothing wrong with seeking a cure ... I mean that’s what medics do, that’s their job and it’s what they love to do and that’s fabulous.... What would finding a cure mean to me? Nothing, because they won’t find one for me. But it will mean that other people won’t have to suffer in the way that I will suffer. I’m not suffering now, I mean I am to a degree, but I will suffer and I know that.’

¹ Calne defines disease as entailing causation, clinical features, pathological findings and pattern of progression. He states that the lack of known causes means that Parkinson's should be described as a **syndrome** – "a group of clinical features that run together and derive from a variety of causes" (2002). Weiner argued that the term "Parkinson *diseases*" would be useful in reminding physicians that "multiple aetiologies are possible to explain the patient's neurologic syndrome." An alternative would be to use "only the descriptive term *parkinsonism* and ...assign numbers to each distinct parkinsonism" (2008).

² Texts mention a condition called Kampavata which was treated with seeds from the *Mucuna Pruriens* plant, recognised as a natural source of therapeutic levels of what is today known as levodopa (see Paralysis Agitans and Levodopa in *Ayurveda: Ancient Indian Medical Treatise*, Bala V. Manyam, Movement Disorders Vol. 5, No. 1, 1990. Pages 47-48/9).

³ Da Vinci's (1452-1519) description of involuntary movements is to be found on an anatomical drawing in the collection of H.M. the Queen at Windsor Castle.

⁴ This is discussed on the Viartis website: <http://viartis.net/parkinsons.disease/treatments.htm>. Viartis are "independent and entirely self-funded medical researchers specialising in PD, based in London, England. Viartis is not part of any other company, university or organisation & have no religious or political allegiances."

⁵ The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care in England. The guideline should be read in conjunction with the national service framework (NSF) for long-term (neurological) conditions (2005) available from www.dh.gov.uk. At time of writing (2014) the guideline for Parkinson's disease is awaiting update.

⁶ This is a message stemming from the medical profession, particularly neurologists – e.g. "No two people are alike. You have to decide what each person needs and treat accordingly" was the 'over-riding message' of the 8th Donald Calne Lecture delivered by Dr. Stanley Fahn in June 2011. See: <http://parkinsonpost.com/2011/06/23/donald-calne-lecture-individualized-treatment-best-approach-in-parkinson>

⁷ Taken from Shakespeare's *Romeo and Juliet* (II, ii, 1-2) when Juliet declares: '*What's in a name? That which we call a rose, By any other name would smell as sweet.*'

⁸ In her lecture 'Where would SHE like to sit? The Personal and Societal Challenge of Chronic Illness and Disability,' Toombs cites cancer, AIDS, **Parkinson's*** and heart disease as the '**dread diseases**' that 'carry with them a particularly powerful symbolic significance.' (Lecture given at the Women and Health Lecture Center for Health Policy and Ethics, Creighton University, Nebraska, 1998). Accessed 10.10.2014 at <http://www.wmeades.com/id244.htm> *In other articles, Toombs substitutes Parkinson's with multiple sclerosis, the disease from which she suffers (cf. Toombs 1995 and 1995a).

⁹ Multiple Sclerosis (MS), like Parkinson's, is an incurable, degenerative, neurological condition.

¹⁰ Leading up to this assessment I had read and heard many stories about autism and concluded that, if

Sam had to be on the autistic spectrum, a diagnosis of Asperger's might be preferable. My preference was doubtless influenced by Frank's observation that 'stories do not simply report past events. Stories project possible futures' (2010, p.10).

¹¹ I have found Bill Gates, Albert Einstein and Isaac Newton to be 'favourites' in conversations relating to Asperger's.

¹² Although ostensibly discredited, the 'refrigerator mother' theory lives on. See, for example <http://www.autism-help.org/points-refrigerator-mothers.htm> The National Autistic Society (NAS) also still feels the need to make reference to it in its Strategic Plan (2011-14, p.3). See **Strategic Plan 2011-2014** at <http://www.autism.org.uk/news-and-events/about-the-nas/documents-and-reports.aspx>

¹³ For discussion on the use of eponyms, see: McCusick, V. (1998). "On the Naming of Clinical Disorders with Particular Reference to Eponyms." *Medicine* 77(1): 1-2. Also, Duque-Parra, J., et al. (2006). "Reflections on Eponyms in Neuroscience Terminology." *The Anatomical Record Part B* (289B): 219-224. For a lively 'Yes/No' discussion, see Woywodt, A. and E. Matteson (2007). "Should eponyms be abandoned?" *BMJ* 335(September): 424-425.

¹⁴ The definition stated that MS was 'an incurable, progressive disease of the central nervous system culminating in total paralysis and death' (Toombs, 1995, p.4). Hindsight has shown her that this is

certainly not the case for all MS patients and 40+ years on from her diagnosis in 1973 she continues in her role as Associate Professor Emeritus of Philosophy at Baylor University, Texas.

¹⁵ On the date I interviewed Sarah, it was actually 195 years since the publication of Parkinson's *Essay*.

¹⁶ Parkinson recognised that anatomic examination was necessary for pathologic knowledge but was clear that his *Essay* was solely clinically based (Kempster et al, 2007).

¹⁷ *Festinant* (from Latin 'festinare' - to hurry): pertaining to a gait pattern that accelerates *involuntarily* as a result of a nervous system disorder. The increased rate of walking represents an automatic attempt by the body to overtake a displaced centre of gravity.

¹⁸ Indeed, for Andrew Lees, a main strength of Parkinson's monograph is "his accurate description of the *course* of the shaking palsy" (2007, p. 331). Italics are not in the original.

¹⁹ Although dates for the Age of Enlightenment are not definitive, it is generally considered to have ended towards the end of the 18th century, or at the time of the Napoleonic Wars (1804-15).

²⁰ Jean Charcot was born in 1825, the year after Parkinson died. He is affectionately known as 'The Father of Neurology' and his recognition of MS as a distinct disease was remarkable at a time when neurological and psychiatric conditions were not viewed separately but rather known generally as 'nervous disorders.'

²¹ The National Parkinson Foundation (NPF) 50th Anniversary Parkinson Report Vol. XVIII, Issue 1, Winter 2007. The NPF was founded in 1957 by Jeanne Levey, whose husband had Parkinson's disease.

²² When Bourke -White was diagnosed with Parkinson's in 1952, aged 48, the role of levodopa as a treatment had not been discovered at that point. Poignantly, she described her ground-breaking brain surgery as a 'cure' (1963, p.369). She died from the consequences of a Parkinson's related fall in 1971 at the age of 67.

²³ Over the years there have been calls for the use of eponyms to be abandoned because 'they are shaped by politics, geography and influence — but never the actual disease itself' (Hopper, T. [Death of the eponym: Naming diseases after doctors is a practice in decline](#)). As a consequence, arguably eponyms may "lack accuracy, lead to confusion and hamper scientific discussion in a globalized world" (BMJ, 2007). Also: <http://news.nationalpost.com/2011/12/02/whats-in-a-name-a-lot-if-that-name-is-hodgkin-crohn-or-alzheimer>.

²⁴ According to Goetz, 'historical documents on PD and descriptions that evoke Parkinsonism from eras prior to the full medical delineation of the disease provide a **continuing source of potential neurological insights**' (2011, p.13).

²⁵ Donald Calne is a British born Canadian neurologist. He was one of the first in the UK to use Levodopa – now a routine treatment - to treat Parkinson's, as well as demonstrate that latent damage occurs in the brain before Parkinsonian symptoms appear. See www.parkinson.org/files/pdfs/parkinson-report/pr-winter-07

²⁶ The Parkinson's UK home page describes the organisation in the following terms: "We're the Parkinson's support and research charity. For more than 40 years we've been working to find a cure and improve life for everyone affected by Parkinson's:" <http://www.parkinsons.org.uk/about-us.aspx>

²⁷ Sheila thinks this of her neurologist: '*Umm, I don't think he's got any understanding of how difficult day to day... life can be... I just don't think he gets it, you know, he hasn't run a home, sort of thing, doesn't know the... He knows it but he doesn't. He knows it in his head but he doesn't know how it feels, if that makes sense.*'

²⁸ Michael J. Fox, an American actor, was diagnosed with PD in 1991 at the age of 30. Although Darren suggests that I must have heard other participants mention Michael J, Fox many times, only 3 or 4 participants referred to him during the course of their interview.

²⁹ Statistics vary and it is interesting that participants tended to use the highest percentage found on websites or in scientific papers. 'Parkinson's occurs due to a loss of nerve cells in the brain. The symptoms of Parkinson's emerge when around 70% of cells have been lost' (PUK website: <http://www.parkinsons.org.uk/content/what-causes-parkinsons>). In comparison - 'When approximately 60 to 80% of the dopamine-producing cells are damaged, and do not produce enough dopamine, the motor symptoms of Parkinson's disease appear.' (National Parkinson's Foundation website: <http://www.parkinson.org/parkinson-s-disease.aspx>).

³⁰ Space does not permit an exhaustive account of developments, but for an excellent introduction see Chaudhuri, K. R., et al. (2011). *Fast Facts: Parkinson's Disease*. Abingdon, Health Press Ltd.

³¹ Source: <http://www.anti-agingfirewalls.com>

³² Source: NIDA Research Report Series (Wikimedia Commons).

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- ³³ Edouard Brissaud (1852-1909) was a French physician and pathologist who succeeded Charcot at Salpêtrière, a celebrated teaching hospital in Paris, which opened in 1670.
- ³⁴ Konstantin Tretiakoff, 1892-1958, was a Russian neuropathologist. He received little acclaim during his lifetime and the paper cited (Lees et al, 2008) aims to recognise “the continuing relevance of his pioneering research on “the black stuff” to our understanding of Parkinson’s.”
- ³⁵ Carlsson, born in 1923, was finally awarded the Nobel Prize for Physiology in Medicine in 2000.
- ³⁶ Hornykiewicz is an Austrian biochemist born in 1926. His paper (2002) was based on a lecture given in London on March 16th 2001, at the invitation of Professor Andrew Lees.
- ³⁷ Echoes of Brissaud can be heard fifty years later when Bourke-White, writing about Parkinson’s, referred to her illness as ‘My Mysterious Malady’ (1963, p.358). See also Appendix 10: Dubiel, H. (2006). *Deep In The Brain*. New York, Europa Editions
- ³⁸ Pinder found that ‘doctors compared and contrasted PD with other conditions.’ She concluded that, for the majority of GPs interviewed in her study, ‘PD did not fare too badly within this hierarchy.’ One doctor, for example, felt ‘there could be much worse things to have, like MS, or a brain tumour, or Motor Neurone Disease.
- ³⁹ Henry (53/67) says: *‘I went to the doctor’s, and initially he wasn’t sure whether it was a familial (essential) tremor or something more sinister. And eventually it was diagnosed as Parkinson’s.’*
- ⁴⁰ Darren (46/47) went to the doctor who *‘thought it was something neurological and told me he thought I might have Huntington’s Disease which I knew enough about to know if it was Huntington’s [...] the prognosis wasn’t very good.’*
- ⁴¹ Angela, diagnosed a year prior to interview, explained she had known little; *‘I mean, I had vague knowledge of it, I mean, everybody has vague knowledge, don’t they?’*
- ⁴² Please see Appendix 12 for brief descriptions of the manner in which Parkinson’s is represented in different types of literature.
- ⁴³ This is reminiscent of the maxim placed in bold on the European Parkinson’s Disease Association website: **‘Parkinson’s is life-altering, but it is not life-threatening.’**
<http://www.epda.eu.com/en/parkinsons/in-depth/parkinsonsdisease/>
- ⁴⁴ This shift is noticeable both in scientific research papers as well as information posted on PD charity websites. See also Appendix 13 for a summary of a talk given by Professor Ray Chaudhuri on Radio 4, April 2013.
- ⁴⁵ Although I cannot include every participant’s story in its entirety, my thesis could not have come into existence without these individual voices in the background. This table is lengthy, but offers the chance to draw on these background voices and put them into dialogue with each other. As Arthur Frank points out, ‘resistance to [injurious] silences begins by making lives narratable’ (2010 p.75); this table is but a small part of that resistance.
- ⁴⁶ Todorova et al refer to the motor stage as the ‘tip of the iceberg’ (2014, p.312).
- ⁴⁷ The Unified Parkinson’s Disease Rating scale (UPDRS) is also a well-established scale for assessing disability and impairment. ‘Studies making use of UPDRS to track the progression of PD suggest that the course of PD is not linear and that the rate of deterioration is variable and more rapid in the early phase of the disease and in patients with the postural instability gait difficulty (PIGD) of PD’ (Jankovic 2008, p. 368).
- ⁴⁸ It was originally published in 1967 in the journal *Neurology* by Melvin Yahr and Margaret Hoehn, and included stages one to five. Since then, stage 0 has been added and stages 1.5 and 2.5 have been proposed and are widely used. Information accessed from European Parkinson’s Disease Association Website: <http://www.epda.eu.com/en/parkinsons/in-depth/parkinsonsdisease/rating-scales/hoehn-and-yahr/>
- ⁴⁹ On the Parkinson’s Association of Ireland website, the progression of PD is comparably described into the following stages: Early Stage; Stable Maintenance Stage; Complex Stage; Palliative Stage. See http://parkinsons.ie/aboutparkinsons_whatisparkinsons_causesandmanagement
- ⁵⁰ Given the absence of a cure for Parkinson’s it has been suggested that the principles of palliative care be ‘applied throughout the course of the disease and not limited to the terminal end of life period.’ Saleem, T. Z., Higginson, Irene J, Chaudhuri, K Ray, Martin, A, Burman, R, and Leigh, P Nigel (2013). “Symptom prevalence, severity and palliative care needs assessment using the Palliative Outcome Scale: A cross-sectional study of patients with Parkinson’s disease and related neurological conditions.” *Palliative Medicine* 27(8): 722-731.
- ⁵¹ When I met the Parkinson’s nurse specialist he had just finished lecturing medical students and kindly gave me his PowerPoint outline which based discussion of disease progression around this 4 stage model.

⁵² Dignitas, founded in Switzerland in May 1998, has ‘the objective of ensuring a life and a death with dignity for its members and of allowing other people to benefit from these values.’

<http://www.dignitas.ch/>

⁵³ For a comprehensive introduction as well as useful links to the different treatments currently used to manage Parkinson’s disease see: <http://www.parkinsons.org.uk/content/drug-treatments-parkinsons>

⁵⁴ “The treatment of PD is ‘alchemy’ produced by personal experience and knowledge, which must take into account the characteristics of each single patient including age, occupation, lifestyle and cognitive function” (Professor Fabrizio Stocci – Institute of Research and Medical Care, Rome).

⁵⁵ Henry explains: *‘I’ve been seeing a consultant privately. But there are some suggestions that in doing that I’ve actually got a worse deal than I could have got through the National Health Service. I mean, for example, [Parkinson’s Nurse] was saying that my drugs regime was outdated and that there were drugs that have been superseded by others that I should be on now. Well the consultant hadn’t said anything about this. I mean the consultant, I mean you might endorse this, we trot along to one of the private hospitals, we see the consultant, we chat for ten or fifteen minutes, he makes a few noises about whether I’ve maintained everything or not, and well, ‘We’ll see you again in another few months.’ And then he sends me a bill.’*

⁵⁶ See Chapter 6 for a much more detailed exploration of how participants’ narratives conform – or do not conform – to Frank’s narrative typology: Restitution, Quest and Chaos.

⁵⁷ Patrick Lewis is ‘a PUK funded researcher.’ It is interesting to note that the PUK website includes this paragraph, referring to Parkinson’s as a ‘devastating’ condition on its web page about James Parkinson. See <http://www.parkinsons.org.uk/content/dr-james-parkinson>

⁵⁸ 1990 was declared the ‘Decade of the Brain’ by President Bush. The 21st century is now viewed by some as ‘The Century of the Brain.’ Currently underway are The Human Brain Project (EU funded) and the BRAIN initiative (Brain Research through Advancing Innovative Neurotechnologies) launched by the Obama Administration in 2013. Tim Lynch is Professor of Neurology at the Dublin Neurological Institute. He has a research interest in the genetics of Parkinson’s disease and atypical dementias (including tauopathies) and the clinical aspects of movement disorders. See <http://www.neurologicalinstitute.ie/medical-specialties-and-clinics>.

⁵⁹ This strapline appears on every web page and all published information.

⁶⁰ For further information please see www.cureparkinsons.org.uk/

⁶¹ http://www.parkinsons.ie/aboutparkinsons_treatments_research

⁶² As for example with Richard’s comment mentioned previously: ‘F*** it, I’ll do that now.’ In these participants’ voices can be heard echoes of some individuals with Spinal Cord Injury: Doug - *‘focusing all your attention on walking again doesn’t let you live life now;’* David - *‘not hoping for a cure doesn’t tie me down to one way of seeing things.’* In Smith, B. and A. Sparkes (2005). "Men, sport, spinal cord injury, and narratives of hope." *Social Science & Medicine* 61: 1095-1105.

⁶³ Gardner is writing about Audre Lorde who, diagnosed with breast cancer in 1978, wrote in *The Cancer Journals*, p.15: ‘Sometimes fear stalks me like another malignancy, sapping energy and power and attention from my work. A cold becomes sinister; a cough, lung cancer; a bruise, leukaemia. **Those fears are most powerful when they are not given voice**, and close upon their heels comes the fury that I cannot shake them.’

⁶⁴ A term used by Dr Atal Gawande in ‘The problem of Hubris,’ the third of four Reith Lectures entitled ‘The Future of Medicine’ broadcast in December 2014.

CHAPTER 5: DIAGNOSIS

“To identify something as a disease or illness is to judge that it is a state of affairs that fails to realise some view of how human bodies and minds ought to be.”

(H. Tristram Engelhardt, Jr.)

5.1 Chapter outline

In this chapter I focus on diagnosis stories. I start by briefly explaining where diagnosis sits in relation to the other two data chapters before discussing the transformative nature of receiving a diagnosis. I then introduce participants’ stories, starting with Janie. I have divided Janie’s story into two parts - her pre-diagnosis story and her account of the moment of diagnosis - and used them to ‘frame’ the chapter. Thus, having first heard her pre-diagnosis story as a ‘whole,’ I have connected a number of participants’ voices and presented them as a ‘shared’ pre-diagnosis story. Taken together, these stories provide the context for a discussion of the diagnostic encounter. I begin the latter with some brief theoretical reflection before moving to individual accounts. The voices offering these accounts build on each other before leading into two ‘extended’ accounts that are important for their richness, as well as their contrasting nature. All these voices move towards Janie’s experience of diagnosis, which I then present as the final story. I conclude the chapter with reflections on this methodological approach and the significance of the diagnosis story within my thesis.

5.2 Introduction

In presenting the overall narrative context in which any discussion of Parkinson’s takes place, the previous chapter exposed some of the ‘culturally shared stories’ about representations of Parkinson’s disease. At the same time, it explored how participants began to develop their personal stories of illness from the ‘broader cultural narratives’ that became available to them after diagnosis (Garro 1994, p.776, Stephens 2011, p.67). In the next (final) chapter, I shall open up and expand on these personal stories of illness through an in depth analysis of three narratives, each considered as a whole. In this chapter, my analytic interest sits with the encounter on which all participants’ narratives are predicated: the moment at which they each received a diagnosis of Parkinson’s.

The power of diagnosis lies not only in its ability to transform apparently random symptoms into an ‘organised illness,’¹ but also, to ‘hail’ people with a new identity of ‘patient-with-a-diagnosis’ (Frank 1997a, p.33). The instant in which a person is ‘hailed’ by a diagnosis has been described as ‘transformative’ (Jutel 2011, p.1); a turning point that not only ‘marks a day when life changes’ (Pinder 1992a, p.2) but divides a person’s life into a ‘before’ and ‘after’ - a division that is ‘henceforth superimposed onto every rewrite of the individual’s life story’ (Fleischman 1999, p.10).^a

Whilst the open structure of my interviews aimed to give participants the freedom to decide for themselves how to story their accounts, it nevertheless employed the same starting point: an invitation to reflect on what it was that led them to suspect that something was not quite right and seek medical attention. Although each participant’s illness narrative is unique, each contained within it a ‘pre-diagnosis’ story leading up to the instant one day in their lives when their doctor (usually a neurologist or specialist in movement disorders) finally ‘unscramble[d] the messages of the symptom to discover the link between signifier and pathology’ (Jutel 2011). In the few seconds it takes to utter a person’s name, participants’ symptoms metamorphosed into a condition that possesses a diagnostic classification and concomitant label - Parkinson’s disease. Participants were no longer following a path characterised by the ‘confusion and uncertainty’ of those living with ‘MUS’ or medically unexplained symptoms (Nettleton, Watt et al. 2005), but now had a ‘route map,’ or, as Jutel describes it, a ‘road map [albeit] in the middle of a forest’ which ‘shows the way – but not necessarily the way out’ (ibid. p.1).

These ‘transformative’ moments not only underpin each personal narrative; they were also the moments that stayed with me long after each interview finished. Frank is clear that DNA is about the relationship between at least two, if not three, elements: a story, a storyteller and a listener and ‘how each allows the other to be’ (Frank 2010, p.16). He is also clear that part of the analyst’s job is to hear those stories that ‘call out as needing to be written about’ (2012, p.43). As I read and re-read transcripts, I realised that the relationship between the story, storyteller and

^a Professor Suzanne Fleischman was a philologist and linguist at Berkeley. She was diagnosed with myelodysplasia, a rare, idiopathic malignancy, and died in 2000 at the age of 51.

listener was often at its most profound during participants' accounts of diagnosis. The latter evoked an emotional response within me (the listener) and, even though I had not been present, I became aware that I attached strong visual images to many of the descriptions I heard. At the same time, many accounts seemed very 'bare' or, in one of my participant's words: 'There was no great ceremony, just "*You have Parkinson's disease,*" that's it' (Julian).

The more interviews I undertook, the more I was struck by the lack of 'ceremony' at the point of diagnosis, as well as a sense that participants' voices were all but silenced during the encounter. This chapter therefore aims to give voice to the diagnostic experience by placing participants' accounts in dialogue with each other. I shall return to Julian's story later in the chapter. First, I turn to Janie (63) who, when I met her, had been diagnosed with Parkinson's for ten years. When I arrived to interview her she explained that she was having an 'off' day^b (i.e. her medication was not working well and she was finding it hard to 'get her feet moving') but she was very keen to go ahead with our meeting. I was able to help practically by making us a coffee and, as we prepared for the interview to begin, she warned me that she might 'fidget.' The latter mainly took the form of moving the automatic leg rest of her chair up and down. As the interview unfolded it became apparent that talking helped distract her from any discomfort she was feeling. As outlined above, I have taken the decision to present Janie's diagnosis story in two parts: her pre-diagnosis story and, later, her moment of diagnosis.

5.3 Pre-diagnosis

5.3.1 Janie's story: 'I just thought it was like a war wound'

For Janie it was seven years of 'diagnostic limbo' until she knew for certain that she had Parkinson's. Her story weaves its way through seven years of symptoms - a shaking leg on waking up from an anaesthetic; clawing toes; a frozen shoulder; a 'ponying' walk (veering to the right); an inability to turn over (when lying down); culminating in falling flat on her face while walking home one evening. Her account darts back and forth in time, and occasionally she has a conversation with herself about whether or not she has correctly recalled the sequence of events leading to diagnosis. Although her account is sometimes a little confusing, and she

^b As discussed at my meeting with the Parkinson's nurse specialist, chapter 3 p.56

clearly wants to get it right for me, she and I both realise – and acknowledge – that the impact of her story does not lie in its chronology, but rather in her ability to convey the confusion and anxiety of those seven years that led to a day which, even in the telling ten years hence, leaves her visibly shaken and emotionally drained.

The lack of diagnosis leads to her living with the conflict of trying to explain away her symptoms to herself (and others) given no apparent medical cause, whilst nevertheless still having the courage to pursue a medical explanation. Thus, when her leg shook uncontrollably following an anaesthetic, she *'thought it was a bit weird'* but recalled that it had been her first ever anaesthetic and that she had been *'very anxious about having it done.'* When her toes started to claw, again she thought it was *'weird'* but refused an operation on her foot to straighten her toes because *'I thought well, it's not doing it all the time, that's a bit silly.'* She refused a cortisone injection for her frozen shoulder from someone who *'didn't even ask, just came at me with a tray with the injection on it.'* Her refusal to have these medical interventions appears, at one level, to be a common sense reaction – why have an operation or injection when the cause of the problem is unclear? On the other hand, she admits to spending *'pounds and pounds on alternative medicine trying to find out what was going on.'* Ultimately, she attributes all these niggling symptoms to a childhood difficulty with her feet that, in older age, had returned to haunt her: *'I just thought it was like a war wound.'*

Janie's narrative is surprisingly visual in its impact. As I re-read the transcript, images of war and wounds populate my mind, alongside a large needle. I am particularly struck by her descriptions of the attempted cortisone injection. I am aware that she has been greatly affected by this incident – not least because she makes reference to it within the first two minutes of the interview and then again fifty minutes later. I am also aware that my interpretation of this part of her story is affected by my own story, for her account re-awakens an upsetting memory of my own from 6 months previously.

My younger son (12), diagnosed with autism at the age of 6, is – amongst other things – asthmatic. Each year he is called for a 'flu jab by our GP practice. Six months before I interviewed Janie, I received the summons. The practice had altered the way it administered the jab and I was informed that rather than an individual

appointment he would simply need to come to a clinic. I spent considerable time preparing him for the latter, talking to him about what would happen, how well he had managed in the past, and that the only real difference between an appointment and a clinic was the uncertain waiting time. Children with autism tend not to be very good at waiting, so as we queued in a very busy waiting area with no real sense of a definite time for entering the nurse's room, I recognised his mounting frustration coupled with anxiety. By the time we were called into the nurse's room, it was clear that she wanted to get things over and done with as quickly as possible. I tried to explain that he was on the autistic spectrum and also hated injections. She was having none of it. He, of course, was very tense, tearful and agitated. As I tried to calm him down and hold him, she seemed to run at him with the needle. It was over in seconds. But of course it wasn't over. That brief encounter destroyed my trust in that particular nurse (whom I had never met before). It destroyed my son's trust in *any* nurses. I had been disempowered in my role as the protector and comforter of my child. He had been traumatised and deprived of the ability to derive comfort from the one person whose words he had believed – his mother.

Perhaps because of my own story, in which I felt deprived of any autonomy in the medical process, I interpret Janie's memory of the cortisone injection incident as evoking a similar apprehension and mistrust. It appears to epitomise the underlying anxiety with which she lived as long as no medical explanation was found for her symptoms, but also epitomises the threat her illness posed - and continues to pose - to her autonomy. Within the first two minutes of the interview, she explained:

'So one guy wanted to give me a cortisone injection. And I thought, didn't even ask, just came at me with a tray with the injection on it and I said: 'What are you doing?' 'We're going to give you a...' And I said, 'But you've not asked me or discussed it with me, you're just going to do it,' and I said, 'No.'

Janie's reaction is in part driven by her professional background of working in mental health, and her narrative exemplifies how cultural and social factors can shape experience, and how a story draws on the "language, ideas, beliefs, ideologies, metaphors and representations" available to the narrator (Hyden 1997; Bury 2001; Nettleton, O'Malley et al. 2004). Janie has spent her professional life trying to 'empower' people, and this strongly influences her response to her own illness and

expectations relating to the management of her situation by other health professionals.

‘I suppose I come from a caring profession where you very much went with what the person needed, you know, mental health is very different to physical needs I know. But, you know, it’s like, where do you want me to be when you’re doing this or that...all the years I worked in mental health was very much about empowering the person to say where they were, do you know what I mean? If they’ve got anxiety and they couldn’t go into a café, I’d say, ‘Well, we’ll go and do it together. I’ll sit here when you go and do something, is that all right?’ And you’d be checking all the time. I think generally people that look after you on a physical level, very often sort of hospitals and carers are sort of like, ‘*Well, just pop up here,*’ and it’s like the chap with the injection for my shoulder, I thought, well nobody’s asked me or suggested it or even explained what you’re doing, you just come marching in here with your big needle, you know, it’s invasive.’

Her account of the kind of dialogue she would have had with her clients brings into the foreground her own need for an empathic understanding of the anxiety that she, herself is feeling. But a second description of the cortisone injection incident, towards the end of our interview, reveals the degree to which she feels let down. Whereas its first appearance is brief, sandwiched between short, almost clipped, descriptions of the seemingly inexplicable symptoms that went ‘*off and on for seven years until I got diagnosed*’ its second appearance not only gains more power through its visual symbolism (‘your big needle’) but also reveals a confidence that has grown as the interview unfolds. It is as though her professional voice has been allowed to enter her personal world, giving her the conduit for fostering a dialogue about her expectations in any medical encounters. Thus, the invasiveness about which she speaks is not only physical:

‘And I think that invades your head as well - your thoughts and your feelings, because you feel like you’re not worthy of being explained things to. No, I think it’s always important to explain what you’re doing and check it out with the person if that’s okay, physically or mentally really. And I think that’s one of my fears that I’ll be in such a state that I won’t have that choice.’

It also highlights how reflecting on a past event may provoke an unsolicited reflection on the future - in Janie's case a future when the Parkinson's may become so severe that her independence of thought and action are compromised. Above all, this part of her narrative highlights how disempowering her own illness experience has been, not least at the moment of diagnosis.

5.3.2 Other voices: 'It sort of creeps up on you'

However, before focusing on the moment of diagnosis, it is important to connect Janie's pre-diagnosis story with different voices that expressed similar experiences. Since space does not permit me to present each participant's story as a whole, I have worked to connect some of the many voices I heard into a 'shared' pre-diagnosis story that will provide context for discussion of the diagnostic encounter. This has also enabled me to introduce a wider range of participants than might otherwise have been possible. As I introduce people I have placed their age at the time of the interview, followed by their age at time of diagnosis, in parentheses.

For a diagnosis to take place, all patients first have to bring to the medical consultation 'a situation that he or she is not fully able to interpret but has assigned to the medical realm' (Jutel 2011, p.81). Like Janie, a number of my participants tried to explain away initial symptoms and did not immediately visit the doctor. Thus, Angela (69/68) put her increasingly illegible handwriting and peculiar walking down to stress, whilst Jean (66/66) thought the inability to lift her arm was due to a damaged tendon after falling over. Richard (60/59) thought he had Repetitive Strain Injury (RSI) on account of the amount of typing he did at work and Kay (51/49) suspected a trapped nerve and then carpal tunnel. Colin (74/63), on the other hand, attributed problems with his right arm to tennis elbow, whereas Sheila (53/44), echoing Janie's experience with her anaesthetic, could not stop shaking after a visit to the dentist. Like Janie, she too explained it away as '*nerves*,' not because it was her first time, but '*because I hadn't been for so many years.*'

As people talked to me about what it was that led them to seek medical attention, many described symptoms which, in hindsight, they now knew were descriptions of Parkinson's symptoms, rather than straightforward, temporary, medical conditions. For Bill (78/73) and Jay (59/53) there was, however, still a degree of ambivalence in

pinpointing when their pre-diagnosis story began, even with the knowledge of hindsight:

‘That’s very difficult because Parkinson’s disease can creep up on you very slowly and I may have had Parkinson’s for years before ... I was diagnosed’ (Bill).

Similarly, for Jay, there was hesitation:

‘I mean, I was obviously aware something wasn’t right, but I didn’t know until really, I mean obviously the family noticed, work – I was slowing right up, you know, I couldn’t work out why I couldn’t get the jobs of the day done.’

And a little later in the interview, when talking about the effect of Parkinson’s drugs in making him feel more ‘*alive*’ he reflected again on the months leading up to diagnosis:

‘I felt I’d been going round like a zombie. Everything seemed like it was because you didn’t realise how bad you were. I mean, my mum realised. She’d seen the change, but of course yourself, it’s a slow sort of...it sort of creeps up on you and you don’t realise how bad you are affected.’

This description of Parkinson’s as ‘creeping up’ on one corresponds with other research into chronic illness, including Mike Bury’s study of Rheumatoid Arthritis (RA), in which he observed that ‘one of the most important features of chronic illness is its insidious onset’ from which he concluded that ‘non-communicable diseases do not ‘break-out’ they ‘creep-up’ (Bury 1982, p.170). However, whereas people with RA were quite often able to hide their symptoms from significant others prior to diagnosis, many of my participants reported stories of other people - including ‘significant others’ - being the first to notice that something was amiss. Indeed, even if they themselves *had* noticed symptoms, seeking medical attention was often contingent on somebody else, some ‘other’ – be it colleague, health professional, stranger, friend or family member - urging them to go to the doctor or making a comment that sowed a seed of doubt that grew sufficiently to prompt them to visit their GP. It is noticeable that many participants used direct speech to report this moment of their pre-diagnosis story, thereby not only highlighting ‘the voice of

specific others' within their story, but also emphasising how, from an early stage, 'no story is ever entirely anyone's own' (Frank, 2012, p.35).

For Jay, employed as an engineer at that time, the 'other' was his manager:

'I was slowing right up, you know, I couldn't work out why I couldn't get the jobs of the day done. It wasn't until my manager came in one day and said '*You're really not well*' – I just had to go. I was persuaded to go to the doctor.'

Adam (69/63) on the other hand, was undergoing an endoscopy when the hospital doctor realised that something was amiss:

'I was gagging on it [the small camera] because I'm not very good at that sort of thing and I started shaking then – and it's after that was done, that's when he [the doctor] said '*I think you ought to go and see a specialist*'.

For a few other people, strangers were the first to comment. Kay, who was taking a break from her work in the caring profession, remembered that:

'The first thing that happened was somebody else noticed.' She was on a walking holiday and 'a chap said to me '*What are you doing with your arm then?*' She was holding her hand as though it had a cup or glass in it, and therefore chose to make a joke of it: 'I obviously am used to drinking a glass of wine and I think I'm still holding a glass of wine or something!'

It was a friend's 'rudeness' that played a role in prompting Richard to see his doctor:

'The first indication was, I guess, about a year before I was formally diagnosed.' He had been at the theatre and an 'outspoken friend' said '*Richard, you're walking like an old man.*' Although he dismissed this comment at the time (in his late fifties) – 'I thought that's just plain rude' - it came back to haunt him when he started to find his walk to work 'a bit difficult.' As a consequence he went to see his GP who said '*Well, you'd better see a neurologist.*'

For Mary (52/44), it was the insistence of family members that finally resulted in her going to the doctor, although she had noticed a number of symptoms herself and colleagues had also commented. As someone who particularly enjoyed sports, she noticed:

‘Extreme fatigue and lack of energy’ and then ‘increasingly I found I was shaking in my left hand when I was tired or stressed, and having difficulty speaking.’ In addition, ‘occasionally people commented that I was limping. I wasn’t actually aware of that.’ But she didn’t go to the doctor’s with it ‘because it was difficult to describe, really, what was going on.’ Even when she felt ‘I was sort of losing control of myself’ and ‘it became more and more obvious to my colleagues.... my colleagues started commenting on it’ – she still did not go to the doctor. For Mary, it was her sisters’ concern, combined with the increasing difficulty in hiding it from her parents, which ‘spurred me on to go to the doctor’s.’

Perhaps the most surprising recall, after 33 years, was that by Edna (77/45). She was severely disabled by Parkinson’s and speaking took intense effort. Indeed, I had speculated that she may find it difficult to recollect the onset of symptoms and moment of diagnosis given the number of years that she had lived with the disease, but it is testimony to the power of diagnosis that she started without hesitation. Again, her use of direct speech was remarkable not only for showing how clearly any one voice (of the narrator) ‘comprises multiple voices’ (Frank 2012, p.34) but also for lending an immediacy to her account. It felt as though she was talking about something that had happened yesterday:

E: ...went to the opticians to get contact lenses

J: **The optician’s to get contact lenses?**

E: and he says to me, ‘*You ought to see a doctor cos you’re only using your right...*’
(Long pause so I interject with...)

J: **the right eye?** (This then prompts her to get the correct word out, which is...)

E: hand

J: **Oh, ok!**

E: And I went to the doctor and she said ‘Yes, well you’re right handed’ and she dismissed it for the... nothing happened...for a while...then a customer – I worked at the bank...

J: **Yes...**

E: and a customer came in, she said ‘*What have you done to your arm?*’

J: **Right**

E: And I went to the doctor’s again, and this doctor immediately sent me to the neur

... (she has real difficulty getting the word out so I decided to help)

J: To a neurologist?

E: Yes, at the hospital, and he said *'When can we make you an appointment?'*

Even when people did finally seek medical attention, it is important to remember that there is no single diagnostic test for Parkinson's. As outlined in the previous chapter, diagnosis remains clinical² and 'there is no 'in-life' marker for idiopathic Parkinson's disease (i.e. arising spontaneously from some unknown cause); the diagnosis can only be made with certainty if Lewy bodies are found in the substantia nigra and other brain regions after death' (Chaudhuri, Clough et al. 2011). Although a number of participants made reference to the lack of a diagnostic test, only Sarah^c (55/42) made reference to death being a pre-requisite for certain diagnosis. She had been subjected to 3 days of tests in hospital before receiving a diagnosis of Parkinson's. She looked me directly in the eye and said:

'So that was their diagnosis, because there isn't a diagnosis. There is no true diagnosis with Parkinson's except when you die and they check your nigra striatum³ has gone black. I know all about it!'

This lack of a straightforward diagnostic test meant that implicit in many stories was the possibility of *misdiagnosis*, as mentioned by the neurologist with whom I met, as well as the potential for people being left, like Janie, in 'diagnostic limbo' (Corbin and Strauss 1988). Both these factors played an important role in connecting participants' stories as they spoke of waiting months, even years, before knowing for certain the name of their condition. These factors also helped connect participants' stories with sufferers of other illnesses, including those with Multiple Sclerosis and 'Medically Unexplained Symptoms' (Corbin and Strauss 1988, Nettleton, O'Malley et al. 2004, Nettleton, Watt et al. 2005, Nettleton 2006).

^c Sarah's story is discussed in detail in the next chapter.

5.4 Diagnostic encounter

“Sick people need physicians who can understand their diseases, treat their medical problems, and accompany them through their illnesses.”
(Charon 2001)

As mentioned in my methodology chapter, I reassembled ‘diagnosis conversations’ from within each interview as part of the process of ‘navigating’ my transcripts and I found that the practice of isolating the diagnosis conversation helped identify both dissonance and resonance between stories. Some of these conversations were narrated more or less as a coherent whole; others emerged more patchily, with reflections later in the interview prompting people to return to the diagnostic moment. Nevertheless, it is important to acknowledge that any accounts within this study rely on ‘retrospective recall several months or years after the event’ (Fallowfield and Jenkins 2004). I am therefore cognisant that any account of diagnosis remains partial, since the people who delivered the diagnosis and are thereby ‘implicated’ in each story have not been able to put forward their own version of events. However, as previously explained, narrative truth involves a ‘structured account of experience’ rather than a ‘factual record’ of what really happened (Josselson 2011, p.225). The way in which participants narrated their stories is important precisely because it reveals how they view and understand their lives; their stories are the means by which they articulated the ‘significance and meaning of [their] experiences’ (Bochner 2001, p.153).

5.4.1 ‘There was no great ceremony’

Returning to Julian’s (54/49) story, he not only commented that ‘there was no great ceremony’ at his diagnosis, but further mentioned that he was in the room for no more than five minutes. Although he was almost certain that he would be told he had Parkinson’s, I remember feeling shocked on his behalf that the diagnosis was so swift; that no space was created in which he might form a reaction; that it was dealt with so routinely:

‘Well, er, I saw initially, umm, er a general neurologist, a chap who described himself as a “jobbing neurologist” which I saw as a rather demeaning, self-demeaning term, but he’s very good and he was pretty sure what it was and he referred me on to the hospital for an absolutely, you know, clear diagnosis with a movements disorders specialist. Umm, she in turn ... she was a German lady, I

remember very clearly, and she just you know prodded me and pushed me and sort of got me to walk and just absolutely matter of factly says “*You have Parkinson’s disease*” and that’s it. “*I will refer you to King’s to have it confirmed again – further confirmed by Ray Chaudhuri*” one of the experts, umm, but there was no great ceremony, just “*You have Parkinson’s disease,*” that’s it.’

For Julian, ‘an unusual beast,’ given his long background in neuroscience research, the manner in which the diagnosis was imparted:

‘...probably shocked me less than it might others.’ He did, however, reflect that: ‘I think it bothered my wife, to be honest, she came along and, er, and I think she was quite upset afterwards. But, er, whether that was the information or, or the way it was imparted I’m not sure I could say. But, but it was just very business-like, simple as that.’

Charles (82/78), diagnosed in his late seventies after noticing ‘a tiny fibrillation’ in one of his fingers, described the diagnostic experience in a remarkably similar way:

‘I went to my doctor and he said, *‘Well, you know, you’ve got a shake but it doesn’t necessarily mean Parkinson’s,’* but eventually of course I had to have it confirmed, and he agreed, of course, that I should be referred to a consultant..... My speech is a little affected I’m afraid, just, not have quite the clarity it used to have. And, umm, yes he confirmed it was – did a test which involved just pushing me behind, from behind, you know, and I sort of staggered and *‘Right’* he said, *‘Yes that’s, that’s Parkinson’s.’*

He returned to this moment a number of times during the interview, revealing how deeply affected he had been by the diagnosis, each time adding another dimension to the reason for his upset:

‘Parkinson’s loomed largely in my mind at the beginning as, you know, quite an insult to me, to my self-esteem [...] I think my identity as a hale and hearty, physically hale and hearty person was very... dented by the... diagnosis, of course, and by the...onset of the symptoms... (takes a breath) and I couldn’t think much else of but, you know, how, what a blow this was.’ Later still, he mentions how ‘I was shocked to discover it was Parkinson’s’ explaining, ‘I got very frustrated with the

Parkinson's of course. Well, having to accept that this was permanent and it couldn't possibly be cured.'

Charles' response to a diagnosis of Parkinson's appears to contest the view, expressed both in the literature and by the GPs with whom I met, that age might 'temper' the impact of diagnosis (Pinder 1992a, p.9). Indeed, the idea that 'older' patients might be able to view the diagnosis with 'more equanimity' because they might see it as 'part of the normal biological process of ageing' (ibid.) is further refuted by the manner of Pat's (72/70) reaction. Also diagnosed in her seventies, she recalled both the brevity and shock of her diagnosis after initially seeing the GP about her shaking hand:

'The GP said *'I don't honestly think after examining it that there's anything wrong with it, [but] I'll send you to the hospital.'* At the hospital '[He] made me walk up and down and then said *'Yes, Mrs X, you've got Parkinson's'* – literally like that. He gave me a form and said *'Go and have a brain scan'* and with that I was shown out of the room. I was absolutely devastated and I didn't tell the children for a month.'

Jutel writes that, in the diagnostic encounter, 'doctor and patient sit in different positions [...] – framed by diagnosis – while nonetheless sharing its impact' (2011, p.63). Arguably, it is a feeling of 'shared impact' that is so absent in Pat's and Julian's narration of their diagnosis and its absence appears even more intense in Keith's (47/29) account.^d In his late twenties, with no inkling of what was wrong with him, he explained:

Keith: I lost the use of my left arm. I, I was carrying it as though it was broken.

J: Right.

K: My doctor booked me into the hospital...I was only supposed to be there for a week, a day, I was there for an entire week. Umm. Loads of tests. Had a CAT scan, where you lie in a big polo mint ...start to look at the laser going across with a badge that says "do not stare at the laser" – bit late for that. Umm - had a CAT scan, loads of different tests, blood, umm, on the Wednesday - I was in on the Monday.... on the Wednesday someone come through and said *'well, Mr X, umm..... we, we know what's wrong with you.'* Then another doctor come up and they started talking

^d Keith's story – including this moment of diagnosis - is explored in greater detail in the next chapter.

between 'em. I had to physically **ask** if they could possibly tell me what was wrong with me, what was my problem. Umm. The second doctor said *'Well you have Parkinson's'* and walked off. So I'm sat there, in a hospital bed... Gutted... absol...terrified really.

J: Yes.

K: Relieved to know that it was...well, not...terminal.

J: Yup. Did you know that straightaway or did you need to ask someone about that?

K: No. I had to ask someone about that. Your first thought is, sat in a wheelchair, in a corner; I'm a seventy-year-old bloke, shaking like a leaf. That is, that is every vision...It's not like that at all. Umm. The second doctor I caught hold of, he said, he said *'Right we'll discharge you tomorrow.'* I said, 'No, not until somebody's been here and explained to me exactly what the problem is.'

J: Mmm.

K: So. I stopped there 'til the following week cos I was going to have to [...] and he explained to me that, umm, *'You have a degenerative.... incurable... lifelong disease....'* which is 3 things you don't really want to hear.

J: Mmm.

K: I was absolutely gutted.

J: Mmm.

K: I sat there and cried for 3 hours.

Not surprisingly, research has shown that an insensitive approach not only 'increases the distress of recipients of bad news' but may also 'exert a lasting impact on their ability to adapt and adjust' (Fallowfield and Jenkins 2004, p.312). The distress in both Pat and Keith's diagnosis stories is tangible ('I was devastated'... 'I was absolutely gutted') and although they do not state it explicitly, their way of 'restorying' this moment in their lives suggests that the manner in which they were diagnosed further compounds the distressing nature of the diagnosis.

Richard, on the other hand, appears to make a distinction between his personal reaction to the diagnosis of Parkinson's and his reaction to the way in which his neurologist informed him:

'He ran me through one or two tests, of which the most intriguing, umm, was to recite the months of the year backwards er, and you're concentrating so much on that it, it allows your tremor to come through and you, you don't try and control it. And it, it, it was very interesting really, you're trying to do something else and concentrating on this mental task and I just found it a very interesting indication of how they diagnose Parkinson's as well as watching you walk and things like that. And he said, '*You've got Parkinson's*' ... and.... I came home and told my wife.'

He described his personal reaction to the diagnosis as:

'...both a relief (that he now knew what it was) and a bit of a bombshell.'

Indeed, it was Richard who, just after we had begun the interview, got up to look for an article, which he then handed me, saying:

'I looked up Parkinson's on, er, Wikipedia and that's a striking sort of a woodcut from a paper in the 1870s or something like that and to be honest I thought 'Fuck me, I'm walking like that.'



Figure 7 Illustration of Parkinson's: A Manual of Disease of the Nervous System (William Gowers, 1886)

However, reflecting on the manner in which the diagnosis had been communicated, he commented later in the interview that:

‘It was matter of fact and I don’t think he could have done it any other way really. It’s difficult, but I hate to tell you this Mr X, but ...Mr X I’m afraid I’ve got some very bad news for you...I mean, what can you do? And I’d half suspected it in any case, so...’

Like Richard, a number of participants ‘suspected’ that they had Parkinson’s, either because their GP mentioned it prior to referring them to a specialist,^e or because they had prior knowledge of it, or through ‘symptom searching’ on the internet. It was noticeable that this ‘pre-knowledge’ seemed to modify the way in which they described their moment of diagnosis and the use of reported, rather than direct, speech had the effect of appearing to reduce the importance of the medical role during this encounter. Barbara (72/70), for example, had developed a Parkinsonian tremor and then a ‘stooped’ walk and felt sure that it was Parkinson’s. Although undiagnosed:

‘I got involved with the local Parkinson’s branch and it became more and more obvious. So eventually in [...] of that year I saw Dr X and he confirmed that, formally, that it was Parkinson’s and put me on some medication.’

Similarly, after Joan’s (55/52) son asked her ‘Why are you walking like that?’ she started searching the internet for answers:

‘Then when I started reading online, which I suppose some medical people might find unhelpful that we can access all kinds of material, I thought - I looked at both Parkinson’s and Multiple Sclerosis. And certainly the sort of things that I was reading on the Parkinson’s information website was matching up with that I was experiencing.’

^e NICE guidelines since 2006 have specified that ‘People with suspected PD should be referred quickly (i.e. within 6 weeks) and untreated to a specialist with expertise in the differential diagnosis of this condition’ (p.6).

Her diagnosis came very much as a consequence of her own research:

‘I went to physiotherapy - I was referred to physiotherapy because my GP was none the wiser. And eventually I sort of felt I’d diagnosed myself really, and by the time I went back to the physiotherapist I said I had these feelings that this is what it must be and they sort of tacitly agreed but said obviously they couldn’t make any diagnosis, but it did look like some of the symptoms.’

When she finally saw a neurologist he agreed that she was manifesting Parkinsonian symptoms.

‘And an MRI scan then confirmed that’s what it was.’

For some, however, diagnosis came having been told that it *wasn’t* or *probably* wasn’t Parkinson’s. In Joyce’s (72/70) experience:

‘Well I first found that my index finger on my right hand started seizing, one of the joints, and very quickly after that I found that my knees were seizing up and I had to go up the stairs on all fours. So I knew something was wrong. I had no idea of a shake at that time whatsoever, although my family told me later that they had noticed it over a year before when they were visiting me. So I went to the GP and he said, *‘Well I’m pretty confident it’s not Parkinson’s.... but I have a colleague and we know him as the ‘shake man’ up at the local hospital. So I’ll get you an appointment.’*

Like Pat, Joyce then received a diagnosis within minutes of seeing the consultant:

‘I was only with the consultant five minutes and he diagnosed Parkinson’s. So I was rather surprised.’

However, for Joyce, the surprise was countered by the consultant continuing the dialogue:

‘So the consultant actually said to me, *‘Joyce, how do you feel?’* First time I’d met the guy, *‘How do you feel?’* And I said, ‘It could be worse.’ And he jumped up from his seat and tapped me on the shoulder and he said, *‘You and I are going to go far,’* he said *‘I like that.’*

As outlined in my methodology chapter, suspense in any story is provided by the ‘tension between different possible outcomes – some to be hoped for and others to be feared’ (Frank 2010, p.32). This lens of suspense might be applied to almost any of the diagnosis stories I heard. However, the tension between different possible outcomes was particularly palpable in Jean’s (66/66) story where, on a second visit to the GP due to a bad arm, he examined her and, to her surprise, said:

‘Well I can tell you one thing it isn’t, it isn’t Parkinson’s’ - and, to be honest with you I hadn’t even thought that it could be.’

After repeated visits to the physiotherapist, she explained:

‘It wasn’t really getting better and she said in the end, she said ‘I can’t really find anything, so I can’t do anything’... So she said ‘I’ll write to the Doctor.’ So I went back to see him, and he looked at me again and he said ‘I’m very sorry’, but he said ‘I have missed something, I think there’s something wrong.’

Of course, as I listened to Jean, we both knew the outcome of this story, and when she said: ‘So, stupidly I’d never thought about Parkinson’s all this time.’ I found myself asking ‘Even after he had mentioned it the first time?’ She continued:

‘No, because he didn’t mention it, he didn’t say ‘I think I was wrong it is Parkinson’s,’ he didn’t say that, he just said ‘I think there is something wrong,’ but he had no idea what it was so he said, ‘I’ll go, I’ll send you to the consultant’ who was Mr X in...’

Within the next breath she was at her meeting with the consultant, still with ‘no idea’ of the possible outcome:

[He was] ‘very thorough, probably examined me for about three quarters of an hour, really everything, you know. My husband went with me and sat, when he’d finished he sat us down in the room and he said ‘You’ve got Parkinson’s’ (pause)... And I just was absolutely gobsmacked.’

I suggested at the outset of this chapter that the relationship between the story, storyteller and listener was often at its most profound during participants’ accounts of diagnosis and how the latter frequently evoked an emotional response within me

as listener. This was one such moment, and I vividly remember feeling relief, albeit tinged with sadness, as she continued her story:

‘Umm. Everything went out of my head, I couldn’t think what I’d got to ask him or anything, you know, umm. He said, umm, *‘It’s very early stages, it’s er, we will manage it, you and I, we will manage it with medication, whatever, it will not affect your life, you’ll be able to carry on [...] you’ll be able to drive and whatever.’* He was very positive which even though I was in this gobsmacking way I thought ‘Oh, that’s good you know.’

In hindsight, I believe that the relief I felt at that moment of the interview related to an unspoken understanding by Jean that ‘the human significance’ of her diagnosis had not been passed over. Furthermore, the way in which Jean narrated her experience reflects and exemplifies the key role that the diagnosis conversation itself plays in these first steps.

Having deliberately retained a narrow focus on the actual moment of diagnosis, I have taken the decision to present two further ‘extended’ conversations before returning to Janie’s story and her moment of diagnosis. These two conversations are ‘extended’ in that Colin’s comprises not only his moment of diagnosis but also a follow up visit to his neurologist, whilst Kay’s includes a conversation that preceded her diagnosis as well as an unexpected – and unusual - encounter after her diagnosis. Their stories offer two detailed yet contrasting exemplars of the diagnostic encounter, and are important for the particular richness of the descriptions contained within them. Both accounts make considerable use of direct speech while recalling their diagnoses and, during the interview, I felt as though I was in the consultation room with them.

5.4.2 Extended stories

5.4.2.1 Colin

At time of diagnosis, Colin (74/63) was employed in two part time jobs, one of which involved writing and meeting tight deadlines. He was referred to a consultant by his GP after a cortisone injection did nothing to improve problems with his arm:

‘And I saw the consultant very early in the morning, and I’d gone on my own because my wife was at work, and when he, I walked into the room he said to me, ‘Just walk up and down,’ and he said, kind of had a look at me and said, ‘You’ve got Parkinson’s disease.’

Earlier, I noted my own sense of unease at the apparent lack of space created for participants to form a reaction to, and ask questions about, their diagnosis at their first consultation. In Colin’s narration, the consultant appears to recognise the need for such a space to be created, at the same time postponing it for the future:

‘So he said, ‘I’m sorry to come out with it bluntly like that, but it’s the easiest way,’ he said. ‘Now, I don’t want you to ask me any questions, because at the moment you’re in shock although you don’t realise it.’ He said, ‘I’d like to see you again in two weeks’ time, I know this is short and sweet, but,’ he said, ‘I have little doubt that you have Parkinson’s. We’ll do some tests eventually but just for two weeks, go home, think about it, read about it and come in and ask me some questions, because any question you ask me now is going to go in there and out there. You’re not with it. And that’s understandable.’

This approach, whilst conveying a sense of the ‘shared impact’ of diagnosis, nevertheless left Colin uninformed about his diagnosis:

‘So I came out and rang my wife and told her. We didn’t really know what Parkinson’s was, you know. You’d heard of it but it’s like anything, isn’t it, the majority of people ... when someone’s had an illness in their family isn’t it, and I’d never heard of Parkinson’s. Anyway we read all about it and [pause] got a little bit wise to it, but still didn’t really know how bad it was in certain ways... and the effect on your life.’

Colin returned for his second appointment:

‘So we went back, my wife came with me when we went back the second time. And he went through things and he said to me, *‘Do you want to carry on working?’* So I said, *‘Well yes of course,’* and he said, *‘Because the option is yours. If you wish to give up working, I understand. Some people do and some people don’t.’* [...] He then decided on what drugs to give me. And he said to me, you know, *‘You can lead a normal life as much as possible but over a period of time the condition will deteriorate, and unfortunately,’* he said, *‘It’s a progressive illness and there is no cure. But,’* he said, *‘the one good thing about it is, there’s no certainty that you’re going to end your life through it, because,’* he said, *‘Parkinson’s can’t really kill you.’* Have you been told that? He said *‘Parkinson’s can’t kill you, but you’ll wind up in the end with something else which has probably been brought on by the drugs.’* [...] He said, *‘unfortunately like everything else, there are side effects to all drugs.’* And he said *‘you’ve got to sort of ... if you take this drug for ten years, you could have ten years of a better life, if you don’t take it, then it will deteriorate quicker so it’s entirely your prerogative. And most people go one way, which is to try and change, but they sometimes give up.’* So I came out from there after the initial interview and I said to my wife, *‘Well I’m just going to pretend I haven’t got it.’* It was the only way I could face that fact that I was never going to get better - because if you’ve got cancer, you always have that chance of having an operation and leading a normal life again.’

Unlike some other participants (p.130), Colin does not explicitly say how he felt about hearing that *‘Parkinson’s can’t really kill you.’* However, as he narrates his story, we are both aware that the prophesied *‘ten years’* have already passed. He has lived with his diagnosis for eleven years and throughout the interview he suffers from considerable dyskinesia. He also endures a freezing episode as he tries to return to his chair after photocopying an article for me. He is unable to *‘get going’* and then suddenly, without warning, his feet start rushing with tiny steps and his whole body lurches forward. Thus, a new immediacy is given to his consultant’s words when he *‘confesses’* that: *‘Really, it’s only recently, in the last twelve months, that I’ve really said to myself that I’ve got it.’* The reason for this acceptance, he explains, is *‘the deterioration,’* before adding: *‘and the knowledge*

that I'm deteriorating.' It is a knowledge founded in those first conversations with his consultant, and now shaped by his own lived experience.

Colin's reflection on his present situation in the context of his diagnostic encounter is just one of many emotional moments in the interview. However, the particular poignancy of this reflection seems to lie in the simplicity with which he articulates the existential challenges facing him. Seen through a lens of suspense, it is a moment in his story that uncomfortably 'remind[s] people that endings are never assured' (Frank 2010, p.32).

5.4.2.2 Kay

At the time she was diagnosed, Kay (51/49) was holding down a full time job in health and social care that involved a great deal of report writing. Like Colin, the problem also started with her arm (as described above), leading her to think she may have carpal tunnel syndrome or a trapped a nerve. After a number of tests that came back negative, she was eventually referred for an MRI scan, prompting her to consider the possibility of a brain tumour. I have included the conversation about the results of this scan as it plays an important role in framing her reaction to her diagnosis.

'I [...] saw the chap who worked in neurology and he said, 'I'm pleased to tell you, you haven't got a tumour.' So I said, he said, 'We're pleased to tell you it's all clear.' That's right he wouldn't have said 'tumour,' he said, 'It's all clear.' So I said, 'So what's happening?' And he said, 'Well nothing, good news.' So I said, 'Yes, but it still means that...' I said, 'I was hoping that you were going to tell me that you'd found something that you could fix it.' And he said, 'Believe you me, it's better that we found nothing.' And I said, 'I'm sure,' and he said, 'But what I want to do is refer you to a colleague of mine who can perhaps throw some light on it. I'll make you a new appointment.' So off I went thinking I was just going to see a colleague of his in neurology, still thinking, 'Well I must have some sort of trapped nerve, why am I seeing a neurologist?'

Kay then went for her appointment with the next neurologist. Speaking with hindsight about this appointment, she mentioned that, while sitting in the waiting

room she saw ‘another chap’ and thought, ‘he walks a bit like me’ but she ‘still didn’t twig.’ She then:

‘...went into the room and he asked me about my symptoms, and he said, ‘*You can’t wash your hair?*’ ‘No I find it really hard.’ ‘*Can’t clean your teeth?*’ ‘No,’ and I thought, ‘He’s spot on, he’s good, he is.’ And he said, ‘*Walk up and down for me.*’ And I thought, ‘Fine he wants to see if I’ve got the walk.’ So he had me sit down and count backwards from 20 and he was watching me and I thought, ‘He’s watching my mouth, watching how I talk.’ But actually afterwards he told me he was watching how many times I blinked and he said, ‘*You don’t, you’re meant to blink so many times in 20 seconds.*’ And I thought, ‘Oh obviously I failed miserably.’ So he said, ‘*Well you’ve got Parkinson’s.*’ So just like that.’

For Kay, the results of her MRI scan with its promises of ‘*good news*’ and ‘*it’s better that we found nothing*’ are suddenly meaningless and she finds herself in a situation where ‘one minute you don’t have it and the next minute you do.’ Whereas Colin’s consultant appears to have pre-empted any reaction, Kay’s consultant appears unprepared for her response which, like Pat and Keith’s, is one of devastation:

‘So I was just really devastated because I just had no idea. And he said, ‘*You had no idea?*’ ‘No.’ ‘*And what did Mr X say to you? What did he think you had?*’ And I said, ‘Well he seemed to be flummoxed, he didn’t know either. He referred me to you.’ And he went, ‘*Hmm. So you obviously had no idea at all?*’ And I said, ‘No.’ So he said, ‘*Well who have you come with today? You’ve not come on your own, have you?*’ And I said, ‘Yes.’ And he said, ‘*Oh don’t tell me, you’re not driving home, are you?*’ And I said, ‘Well yes.’ And he said, ‘*Well you can’t drive home.*’ So the nurse was there and so he said, ‘*Are you going to get her some tissues?*’ So she went off to find me some tissues because there weren’t any handy, for some reason or other. And he said to me, ‘*Well you won’t be able to go home, you’ll have to get somebody to pick you up.*’ So I was crying all the time. And he was just looking like he didn’t know what to do with himself really. So he said, ‘*Well what I’ll do, I’ll go and speak to the specialist nurse, no go and speak to one of the nurses and I’ll get the specialist nurse to call you this afternoon and talk you through it,*’

because clearly I had my 10 minute slot and he didn't have time to tell me anything or pacify me or give me any leaflets. I just had to leave the room then.'

As she narrates her story, I sense that Kay is back in the consulting room. She feels again the shock of her diagnosis and implicit in her narration is a feeling that her upset, like Pat and Keith's, relates as much to the manner in which she was told her diagnosis as its distressing nature. Then, in a fascinating post-script to her diagnosis, the implicit is made explicit. Arriving at someone's house for a Parkinson's support group meeting Kay, to her surprise, sees her consultant there:

'From when I walked in there, I could see him sat on the sofa and nobody was sat next to him either side. [...] And he said, *'I've noticed that no one wants to sit next to me.'* And I said, 'I won't sit next to you, last time I spoke to you, you traumatised me.' And he said, *'Oh I know I did, I'm sorry about that.'* So he said, *'There's no easy way really to tell people.'*

Although Janie (see analysis below) challenges the manner in which her diagnosis is delivered, her doctor appears to remain silent. By contrast, Kay's challenge leads to a dialogue between her and her consultant:

'So a bit later on he was having a question and answer bit. So I said that I understand that you only really get a ten-minute slot or whatever it is to see people, it could be twenty minutes. But I said, 'I felt that it was quite harsh, the way that you told me.' And he said, *'Well how could I have done it differently?'* And I said, 'Well, you know you just blurted it out, maybe you needed to warn me.' And he said, *'Okay,'* he said, *'It is hard, I don't always know what to say.'* He said, *'Sometimes it's just better to come out and say it, rather than, you know.'* And I suppose everyone is different. I mean he was direct. But I mean to me if he'd have said, *'Well I'm afraid I'm going to have to tell you that you've got Parkinson's'* rather than *'You've got Parkinson's.'*

Kay's experience illustrates the crucial role played by the diagnostic moment in 'facilitating' or 'inhibiting' the patient-doctor relationship' (Jutel 2011, p.63). She is fortunate that, following a diagnosis that clearly 'inhibits' this relationship, the unanticipated meeting with her consultant results in the chance to re-establish 'empathic relations of care' through listening and dialogue (Frank 1995, p.109).

‘But he turned out to be okay and he was really helpful and he answered our questions and, you know, he really wants to do the best for everybody [...] And I’ve seen him quite a few times and he’s been quite positive and quite informative. And so I’ve forgiven him now!’

Kay’s opportunity to confront her consultant on neutral territory a few weeks after diagnosis was unusual and none of my other participants reported experiencing a similar opportunity. However, as will become clear from Janie’s narrative, she tried to tackle her diagnosing doctor at the time. I return now, to the moment that Janie heard that she had Parkinson’s disease.

5.4.3 Janie’s story: ‘I can’t be doing with this’

As she talks about the moment of diagnosis, it is clear that Janie is not like many of Habermann’s participants who “were in shock and did not recall the dialogue between themselves and the diagnosing physicians” (1996, p.404). Rather, like S. Kay Toombs^f writing about her diagnosis of Multiple Sclerosis (Toombs 1995), she is able to remember and relive the moment from 10 years previously and I hear the emotion and adrenalin in her voice as she recalls the dialogue with the doctor who diagnosed her.

‘He was sort of testing me, all this business (at this point she gestured towards me with her hands outstretched, turning them at the wrist)... cognition. And various things and he said ‘*I’ll just go and see...*’ I can’t remember his name now, the consultant. And they were in another room, and this was bad... The door was slightly ajar and I heard the consultant say ‘*Oh, that’s Parkinson’s.*’ And I just sat there and thought ‘Jesus,’ sorry, because my uncle had Parkinson’s. My mum’s brother.’

Listening again to the interview, hearing the break in her voice as she says ‘*Jesus*’ followed by ‘*sorry,*’ and knowing what is coming, I now sense that she is seeing again the open door, hearing again the disembodied voices. At this point, worlds collide; so many different stories - as yet unspoken - intersect, and the interest of her

^f Toombs opens her article about living with MS with the following bold statement: “Every Multiple Sclerosis patient can remember the moment of diagnosis. It is one of those events that can forever be recalled in the most exquisite detail... (down to being able to) repeat verbatim the words used by the neurosurgeon” (p.4).

story lies both in what is spoken as well as what remains unspoken. I am particularly struck by the way Janie reports the consultant's words, her tone of voice as she reports the words she overheard him say: it comes across as off-handed, dismissive, not even important enough to be the 'eureka' moment that Pinder describes when concluding that diagnosis of Parkinson's is a point of 'maximum theoretical coherence' for the medical profession (Pinder 1992a, p.5). Janie and her story remain invisible to him as he remains behind the door.

Janie is cross with her doctor, and yet she does not express to him what I understand, from different parts of the interview, underlies her deep shock at being diagnosed with Parkinson's. Her instinctive response is to feel aggrieved by the lack of professionalism and she does tackle the doctor on this:

'I've just overheard what you said.' And I was all sort of sparky, you know, sort of cross. And he said '*Yes, let me have a go*' and he sort of did it, and he said '*The cognition in your wrist tells me you've got Parkinson's.*'

Janie's story now becomes less coherent, darting back and forth in time, making it feel somewhat disjointed. Whereas this may be an 'ordinary' moment for the doctor, Janie refers to feeling 'mortified' and yet she drove back to work. Not only has she had the upset of the diagnosis but, in addition, I learn that on that same day she ran away from an MRI scan, again underscoring her negative experiences through an apparent lack of agency:

'I was mortified. And I was driving all the way back to work. Before that, they'd sent me for an MRI scan, and I didn't realise what it was. I'm claustrophobic. I got all undressed, got on this table and they started to strap me down and I said 'I'm sorry, I'm not going in there' and I bolted. So that didn't work! So that was the day I knew, and...' (Her voice trails away as she remembers).

She then returns to her feelings on hearing the word Parkinson's through an open door:

'Yes, it was just shock. [**J: Yes**] I thought, oh my God. You know, I'd already passed the MS thing through my head because my mother-in-law had had MS. And it was just the big name really. Like you were just waiting for him to say '*Oh no,*

it's just this, or just that,' but it was somehow having that name [Parkinson's] frightened me witless.'

Janie's simple yet powerful description of how she felt on hearing her diagnosis not only strongly echoes the voices of other participants, such as Sarah, Jean, and Angela (Chapter 4) but also helps illustrate the view that "diagnoses, especially those that relate to serious illness, mean much more to patients than simply the identification of a particular disease state" (Toombs 1995a, p.3). Indeed, expanding this notion further, Suzanne Fleischman proposed that the verbal act of presenting a patient with a diagnosis is "never a simple act of conveying value-neutral biomedical information," but rather "an act fraught with symbolism" which has the potential "irrevocably [to] alter the person's consciousness, view of the future, relationships with family and friends, and so on"(1999, p.10).

Striking in Janie's diagnosis narrative are the silences and, as the interview unfolds, I am aware that making her story 'narratable' does, indeed, involve 'telling openly what had been secret' (Frank 2010). A further twenty minutes into the interview she reveals just how 'fraught with symbolism' the diagnosis has been when, referring to her uncle, she states very simply:

'Well, my only thought came up – he died quite young.'

I cannot help but wonder how differently Janie might have reacted to her diagnosis had she not remained silent about her fears but rather expressed them during that diagnostic encounter. S. Kay Toombs, reflecting on the 'power of words and images to shape reality,' surmised that because of the way her diagnosis had been handled, and the world of MS that she had built in her head, she therefore "interpreted every insignificant muscle twitch as a portent of disaster" (1995, p 6).

But despite her background working in mental health, and talk of helping empower people to 'say where they were,' Janie's crucial medical encounter results in her remaining silent about 'where she is.' Janie's interpretation of her diagnosis is guided by a lack of information from the doctor who diagnoses her and – unbeknownst to him - the story she retains through the images of her uncle. She puts the lack of information from her doctor down to the brevity of the meeting and:

‘I think Dr X himself was a bit shocked himself, you know, and he said *‘Well, you know, we’ll get on to the Parkinson’s nurse.’*

She did not actually see the Parkinson’s Nurse until two months after diagnosis. In the meantime:

‘That weekend (after diagnosis) I was in the local bookshop and I bought a book, it’s still down there (gesturing to a bookshelf), and of course it goes through everything from hallucinations to...’ (She cannot bring herself to articulate whatever memory she is reliving) ‘...because you don’t know enough, in that time you’re there (in the consultation), they don’t really tell you very much about what that means. You know, you’ve heard the name and my uncle had it and I knew people shook but I wasn’t doing any of that.’

For Janie, the diagnosis is frightening in part because of her ‘second hand descriptive knowledge’ (Pinder, 1992, p.14) of Parkinson’s. And yet, the inherent fear that someone else’s story may become her own is further confused by the fact that what she thought she knew about Parkinson’s (people shaking) is not actually happening to her.

Her story becomes a poignant blend of past anxieties and future apprehension – neatly illustrating Frank’s observation that ‘Stories do not simply report past events. Stories project possible futures’ (2010, p. 10). Remembering how she first started informing herself about Parkinson’s reminds Janie of how many years have passed since diagnosis, prompting her to think about the future and, in turn, remember the contents of the book that so upset her at the time; contents that vividly illustrated the future towards which she is heading:

‘Ten years ago wasn’t it?’ Yes, ten years ago now. So it’s like, ‘where is it all going to end, you know? Where will it go, how fast will it grab me, you know?’ Reading the book I’d picked.... (she then talks briefly about telling or not telling others about her diagnosis before returning to the book)...it was before the days of having the computer and Google, I sort of bought, as I said, I bought that book and I flicked through it, went and had a coffee and flicked through it in the town and I thought, ‘Oh my God.’ All these things came up, you know, ‘I can’t be doing with this.’ I actually put the book away for quite a long time...’

This seems particularly relevant to Janie's experience, which neither allows her to 'tell the whole story' at the time of her diagnosis, nor does it enable her to ask the most frightening questions. Rather, she is left trying to contain her fears through the symbolic act of putting away the one book she has bought.

I found myself aggrieved on Janie's behalf: aggrieved that she was left alone, only 53 years old, having acquired a new, unwanted identity, yet now driving back to work with little understanding of her future other than through her teenage memories of the uncle who had died young as a consequence of Parkinson's.

5.5 Discussion

By focusing on the moment of diagnosis in this chapter, my aim was to give voice to those stories that called out as needing to be written about, as well as those that might not otherwise have been heard (Frank, 2012). Whilst my decision to place stories of diagnosis centre stage was in response to this methodological commitment, the need to do so was further driven by the lack of detailed discussion and absence of stories in the literature:

'Every day Parkinson's patients are reminded by numerous incidents of what things were like in the past. Many look back with sadness of what has been. To some, the moment the diagnosis was given is painful (**as is how this was done**). Many need time to come to terms with it' (Van Der Bruggen and Widdershoven 2004, p.293, emphasis added).

'[Most participants] were in shock and did not recall the dialogue between themselves and the diagnosing physicians' (Habermann 1996).

Above all, I tried to give 'evocative force' to participants' stories, gathering their voices so that they might be heard collectively (Frank 2012, p.36). This was not in order to present a unified view but rather in an attempt to hear different voices as they came into dialogue with each through expressing their views on a similar event.

In the process of working with participants' stories about diagnosis, it was important not only to listen to *what* people were saying, but also the *manner* in which they said it. According to Frank, ill people's stories are 'polyphonic' insofar as 'each story

merges voices⁸ (2012, p.35). Whilst I found this generally to be true, I would argue that, within my participants' narratives, there were important moments where voices, rather than merging, emerged distinctly from amongst the polyphony. These moments correlated with turning points in participants' lives, perhaps the most significant of which was the moment of diagnosis.

As can be seen in the stories above, it was at this point of their narration that many participants employed direct speech to recall the words used by their diagnosing doctor (usually a neurologist). The effect of this was powerful in a number of ways. From my perspective as listener, it felt at times as though the diagnosing doctor had joined the interview. More importantly, it appeared to take participants back to a moment when they had entered the consulting room as their 'prior' selves and left it with their new identity of 'patient-with-a diagnosis' (Frank, op. cit.); it returned them to a point pre-dating any need for the medical voice to merge with their own, singular voice, whilst at the same time marking the moment at which the relationship with their doctor changed forever. I was left in no doubt as to the 'human significance' of each and every diagnosis, at the same time haunted by Habermann's observation that for many of her participants, the human significance was 'passed over' (op. cit.)

For each of my participants, diagnosis happened in a 'life that already has a story' (Frank 1995). Of course, the story continues after diagnosis, but it is changed both by the disease itself as well as individual responses to the medical, social and cultural context in which it unfolds. How individual stories unfold is the focus of my next chapter, when I build on the 'human significance' of diagnosis explored in this chapter, within the context of the 'master narrative' explored in the previous chapter.

⁸ Frank here uses the word 'merge' in the sense of 'losing identity in something else' (The Chambers Dictionary).

¹ Peter Conrad, Professor of Social Sciences, Brandeis University, paraphrasing the physician, Michael Balint, in the foreword to Annemarie Jutel's book on diagnosis, 'Putting a Name to it' (2011).

² "Remarkably, the original clinical description of the disease [i.e. as described by James Parkinson in 1817] remains a landmark reference, especially with regard to the motor features." Massano, J. and K. P. Bhatia (2012). "Clinical Approach to Parkinson's Disease: Features, Diagnosis, and Principles of Management." Cold Spring Harbor Perspectives in Medicine (2): 1-15.

³ The nigrostriatal pathway, or the nigrostriatal bundle (NSB), is the dopaminergic pathway that connects the substantia nigra with the striatum. The substantia nigra actually loses its blackness as a consequence of Parkinson's – see illustrations on p.127.

CHAPTER 6: PATIENTS' NARRATIVES

6.1 Chapter outline

In this final data chapter, I build on the previous discussions of the 'disease story' and 'diagnostic encounters' by presenting the illness narratives of three participants: Rory, Keith and Sarah. As discussed in my methodology chapter, I have used Arthur Frank's typology of narrative forms as a 'listening device' in order to hear how each of these three participants employ the narrative resources that become available to them as their experience of illness changes over time. Within the context of this thesis, these were three of the stories that 'called out' most strongly to be written about. My aim is not to present 'typical' stories, but rather to show that 'each person's story can remain unique while being representative in that uniqueness' (Frank 2010, p.116).

I begin the chapter with a preface, telling a story that helps illustrate not only the social and medical context framing participants' narratives, but also provides an example of how my own understanding was expanded and shaped during the research process. I then provide a table summarising the characteristics of Frank's key narrative types before presenting Rory, Keith and Sarah's stories.

6.2 Preface

April 11th, the day on which James Parkinson was born in 1755, is marked every year by World Parkinson's Disease Day; April is designated Parkinson's Awareness Month within which, in the UK, the various Parkinson's Charities set aside a 'Parkinson's Awareness Week.'

In 2012, the latter took place just as I had reached what, in hindsight, I now know to be the halfway mark of all the interviews I was to undertake for this study. I had interviewed 19 people with Parkinson's and, unbeknownst to me, still had the pleasure of a further 18 interviews and a multiplicity of stories waiting to unfold.

During that particular Parkinson's Awareness Week, I attended various local PUK group meetings, at one of which I found myself next to a woman with considerable dyskinesia. As we sat talking over a cup of tea, post cards from the national headquarters were distributed to each table with a request for them to be completed

both by people with Parkinson's and also their Carers. On the card was the question: "*What would a cure mean to you?*"

My neighbour asked what the post card was about. As I responded, I remember struggling to sound neutral and matter of fact. I actually felt quite upset and cross. It was immediately apparent to me that she would not be able to complete the post card by herself since she would not be able to hold a pen. There were also a number of wheelchair-bound people in the room, unable to lift their heads off their chests, so severely had they been affected by many years of Parkinson's and its degenerative effects.

Although quotes culled from the cards might serve the pragmatic needs of a fundraising department,¹ I found myself questioning whether it was morally right to ask people, without warning, to contemplate what a cure would mean to them, since implicit in this act was the requirement that each person recover a former image of themselves whilst at the same time acknowledging that their lives had been irrevocably changed by their illness.

The woman next to me asked whether I would scribe for her. It was quite hard to hear what she was saying as the dyskinesia had left her breathless, able only to talk in short, rapid, breathy phrases. As I wrote on her behalf, I took the liberty of expanding her phrases into sentences by adding a couple of pronouns and conjunctions. Perhaps it was my way of 'recovering' her. Of more interest, though, was how she chose to answer this question, for instead of engaging in a narrative involving a prospective cure, she instead chose to describe the very real consequences of Parkinson's for her and the way in which she had managed to accommodate it in her life. In a few simple words she appeared to assert a sense of moral agency as she explained:

[It] means curtailing all my activities, lost my job – [and] yet, on the good side [I've] met lots of nice people, time for my family [and] have found an inner peace.

My reasons for telling this story are twofold:

Firstly, reflecting on the emotional response I experienced at this meeting is a valuable reminder that, as researcher, I am very present in this thesis and must remain alert not only to the lens through which I view and interpret my participants'

words and actions, but also to the effect my presence – through both my words and body language - may have had on what participants chose to tell me during the course of their interview.

My instinctive response to the post card activity was, I realise, shaped both by the immediacy of sitting next to somebody so badly affected by Parkinson's that she could not, of her own accord, take part in the activity, and also by my recent experience of eliciting participants' views towards medical research at some stage during their interview.

Over the course of 19 interviews I had become sensitised to the emotional demands involved in discussing their lived experience of Parkinson's, for to do so demanded that my participants reflect on past, present and future: a past in which they had been free of Parkinson's and its deleterious effects; a present, involving acknowledgement of the number of months or years that had passed since diagnosis and the 'stage' of the disease they had reached; and a future riven with uncertainty – and, in their view, no cure.

Secondly, I tell the story because this post-card activity succinctly illustrates both the social and medical context that frames any discussion about Parkinson's. Asking people to consider "What would a cure mean to you?" points to - and is the consequence of - recent advances in medicine which have led to a 'resurgence or intensification of biomedical approaches to 'understanding' and so solving the problem of illness [particularly] in relation to neurological 'conditions'" (Nettleton 2006, p.1175). It highlights how restitution - a return of the sick person to 'the status quo ante' remains 'the culturally preferred narrative' (Frank 1995, p.83). The latter is a story that features [good] health as the 'normal condition that people ought to have restored' (ibid. p.77) and is, not surprisingly, the narrative with which, as a society, we are most comfortable, despite the increasing numbers of people affected by chronic illness. Arguably, it is this concept of restitution that both feeds, and is the consequence of, social expectations, since anyone who becomes sick wishes to get better. Thus it is the narrative that 'medicine can most easily hear' (Nettleton, O'Malley et al. 2004, p.50). And yet it is important to be aware that within this narrative resides an inherent danger – the danger that 'medicine's hope of restitution [may] crowd[s] out any other stories' (Frank, p.83).

Before beginning my interviews I had anticipated that how people talked about their past - through describing their story leading up to and including diagnosis - may be a helpful indicator of how they perceived themselves in the present. What I had not anticipated was the degree to which occasional references to medical research might reveal participants' current understanding of self. I had also not anticipated the degree to which talking – or preferring *not* to talk – about medical research would help untangle ‘the different threads in the fabric’ of their stories, thereby allowing me to hear how stories are woven together as well as ‘what changes in storytelling occur over time’ (Frank 2010, p.119).

6.3 Table summarising characteristics of Frank’s key narrative types

Illness narrative type	Characteristics
Narrative type	“The most general storyline that can be recognised underlying the plot and tensions of particular stories” (p.75)
<p><u>Restitution</u> <i>“Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again”</i> (p.77)</p> <p>Restitution stories are “<i>self-stories only by default</i>” (p.115)</p> <p><i>“When restitution does not happen, other stories have to be prepared”</i> (p.94)</p>	Restitution implies the triumph of medicine. Illness is an aberration; sufferings of illness will be relieved; Illness is temporary and transitory; the body is an “it” to be cured; predictability will be restored; breakdowns can be fixed → “I’m fine,” “I’m good as new;” emphasis on cure, a return to status quo ante and a future that will not be disrupted. Restitution forestalls any intimation of mortality.
<p><u>Chaos</u></p> <p><i>“Troubles go all the way down to bottomless depths. What can be told only begins to suggest all that is wrong”</i> (p. 99)</p> <p><i>“Chaos stories remain the sufferer’s own story, but the suffering is too great for a self to be told”</i> (p.115)</p>	Sense that no one is in control; life will never get better; no sense of purpose; sometimes beyond speech; lack of control & failure to reassert predictability; reveals vulnerability, futility, impotence; emotional battering fundamental to chaos; provokes anxiety in others – any of us could be sucked under; dismissed as ‘depression’; story lacks narrative sequence and can only be told retrospectively. Danger that story is silenced or the sufferer steered into another narrative type.
<p><u>Quest</u></p> <p><i>“Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person’s belief that something is to be gained through the experience.”</i> (p.115)</p> <p><i>“The quest narrative affords the ill their most distinctive voice”</i> (p.115)</p>	<p><u>Quest memoir:</u> Gentlest form of quest story; incorporate illness into one’s life; told stoically; no special insight claimed.</p> <p><u>Quest Manifesto:</u> Least gentle form of quest; there is a truth to be told; silence is the enemy; illness is a social issue; call for social action and change.</p> <p><u>Quest automythology:</u> The survivor is reborn, acquires a new identity through self-reinvention. Emphasis is on individual change rather than social reform.</p>
<p><u>Life as Normal</u></p> <p><i>“Declines to share illness experience...in order to preserve other experiences”</i> (2013, p.194).</p>	Seeks to minimise illness; illness story is waiting to be told but the moment is not yet at hand.
<p><u>Broken narrative</u></p> <p>In the case of those who lack the capacities for storytelling, such as speech or memory, they are: <i>“Telling a story against the odds that a story can be told”</i> (2013, p.203).</p>	Less about content of the story – the story is not about illness. The act of co-constructing the story enables the continuing narrative capacity of the person who is severely incapacitated.

Table 13 Summary of Arthur Frank’s Illness Narrative Typologies from ‘The Wounded Storyteller: Body, Illness & Ethics’ (1995; 2013).

6.4 Rory

6.4.1 'A temporary glitch'

Rory had been diagnosed two years prior to my interview with him, although as his story unfolded he explained that at diagnosis his neurologist '*estimated I'd had it for four years...but it could be longer than that.*' As with so many other participants, the story leading up to his diagnosis strongly suggests belief in, and anticipation of, restitution, despite the impetus of the story arising from a '*breach in the expected state of things*' implicit in which lies the potential for chaos. For Rory, the 'breach' appears in the form of difficulty flexing and extending his fingers as his left hand becomes '*slower and less able in general,*' but this feels like '*a temporary glitch, it felt like any second now I was going to suss it and it would be in place and, you know, it would rectify.*' It is only when he goes to see a physiotherapist for an unrelated sports injury and therefore thinks to seek her advice about his hand that his restitution narrative begins to falter as he observes that '*she looked a little bit aghast...a little bit concerned*' and refers him back to his GP.

In comparison with some participants, Rory's 'diagnostic limbo' is short: a matter of months rather than years, and despite the Physio's concern, restitution remains to the fore when referral to a rheumatologist results in his being sent for tests and scans. He describes himself as being '*fine*' and '*entirely relaxed*' about the various referrals, even noting that questions asked of him - which in hindsight he now knows pointed to Parkinson's - did not, at the time, prompt him to ask what they indicated:

'He asked me whether I had difficulty getting in and out of a car. And I said, 'Well funnily enough, you know, I have noticed recently that it is becoming more difficult to get in and out of the car.' '*Do you have problems turning over in bed?*' 'Well yes, funny you should mention that as well.'

It is when Rory talks about his referral to a neurologist that the narrative timbre changes. There is a greater sense of urgency as he explains that '*about this time I'd started to realise there was something fundamental wrong.*' Catching sight of himself in a mirror he realises that his posture is incorrect and that '*the left side shoulder had sagged and turned inwards. And it was very strange.*' The restitution

narrative becomes much harder to maintain both in the absence of a diagnosis and in the strangeness of the reflection thrown back at him by the mirror. It is at this point – and prior to any meeting with his neurologist – that the ‘I’ in the narrative changes to ‘we’ (he and his wife), and as they search online for an explanation for his symptoms it is apparent how easily one narrative type may interrupt another.

‘It’s just as well I can’t see myself in a mirror, I think, because I was walking up from town-and there’s an alley actually which is a shortcut, a shorter away down to the train station - I was walking up and they’re having a chat, my next door neighbour who knows I’ve got Parkinson’s and a guy who lives next door to him, er, and he’s rather a salty guy, not the immediate next door neighbour but the one beyond, and he said ‘*Come on, shape up there, walk properly!*’ and you know.... It was meant to be jocular – it was slightly uphill actually, and, and I thought ‘Oh no!’ (said in a slightly despairing tone) You know...this was a real downer, I thought. You’re walking, you know, people are noticing you’re walking like an old man! (laughs with a resigned tone) And I thought, ‘Oh no, is that really what I look like?’ And I must admit, I had thought that the drug treatment had fixed it, but evidently, evidently not completely.’

Table 14 Self-perception, mirrors and drugs: reflections by Richard

At the click of a button they discover Parkinson’s as a possibility but discount it as he is ‘*far too young*’ and because they understand Parkinson’s to be ‘*a symmetric problem and not an asymmetric problem.*’² Chaos intrudes as he decides he may have Motor Neurone Disease (MND), a realisation that causes him to ‘*visit the toilet rather rapidly and that was a bit alarming.*’ Alongside the possibility of MND comes that of Multiple Sclerosis (MS) but despite these incursions, he remains ‘*convinced for an awfully long time that it was a trapped nerve up near the spine, near my shoulder.*’ This is a symptom he can comfortably normalise since, over the years, he has experienced sports injuries to his shoulder. Kay experienced something similar after her arm stopped swinging; her typing deteriorated and her wrist ached. Her GP, thinking it may be carpal tunnel, sent her for nerve conduction tests (Rory, too, had these tests) but when the results came back negative:

‘He sent me to a physiotherapist to have some physiotherapy. And she took one look at my hand and said, ‘*No you haven’t got RSI, you need to get back to your doctor.*’

Went back to my doctor, told him the results, it was obviously on the file and he was stumped really, didn't know what it was. And said it might, I think, I don't know whether he said it might be trapped nerve. That's what I started to think it was, and I had a trapped nerve in my neck or my shoulder, on top of my arm that was causing this problem, because nothing else was affected.'

However, Rory's conviction is pierced when:

'I saw the neurologist who very, very casually watched me walk up the corridor, down the corridor, did the tap test between index finger and thumb, tested my wrists on my left hand and right hand and said *'Have a seat'* and discussed the diagnosis: *'Well, you've got Parkinson's'* - just like that.'

6.4.2 'Google it and see what you make of it'

As if by way of explanation for the *'just like that'* aspect of his diagnosis, he explains that his diagnosis was done through a private clinic:

'So whereas normally you might have been expecting to go and talk to the Parkinson's Nurse or somebody else with a broader education in what the implications of that are, there was no one here. I was just told that and told to come back two weeks later - 'Google it' and see what I made of it.'

As I listen to Rory's interview again I hear echoes of other participants' *'just like that'* stories. I hear again Kay's diagnostic encounter (chapter 5) where she commented that, after asking her about symptoms and observing her walk and blink, her diagnosing neurologist said: 'Well you've got Parkinson's. So, just like that.' But I hear, too, others, such as Zoe and Mary:

Zoe, at 29, had similarly undergone many tests and scans, only finally 'to see a consultant neurologist...and, umm, he immediately told me that it was Parkinson's...just by looking at me...really...I obviously had that Parkinson's face.... that look. He did a few tests, there's a rigidity test and that kind of thing ...but he basically just...said it was Parkinson's and sent me on my merry way.'

Mary, at 44, had also experienced considerable diagnostic limbo so that ‘When I actually got my diagnosis, it was fairly quick. I sort of tell the story, you know, [he] made me touch my nose a couple of times, and said, *‘It’s Parkinson’s, off you go.’* It wasn’t quite like that.’

Table 15 ‘Just like that’ stories

I encourage Rory to say more, asking ‘You were told to ‘Google’ it?’ As I listen back to the interview, I note my voice remains unemotional. However, there must have been a look of surprise on my face because Rory continues with *‘to be fair to the neurologist...’* and I hear myself apologising and saying *‘Sorry, I’m expressing surprise.’* It is an active reminder of the process of co-construction during the course of my interviews. My surprise is in part because I know the effects that googling has had on Rory in the lead up to his diagnosis – effects of which the neurologist seems unaware. And even though Rory now knows his diagnosis, Zoe’s voice resonates in my head as I recall that, left with a few months between her first and second opinions, she searched the internet – *‘And then I stopped because I’d read what I didn’t want to read...’*

In hindsight I am glad my face showed surprise, for it results in Rory elaborating on the diagnostic encounter in a way that might, otherwise, have remained silent:

‘Yes, and he said, to be fair to the neurologist he did, he did warn me to be careful with my reading material and choice. But he said, he described it as probably the most benevolent of the neurological conditions he diagnoses. He said it was a very slow disease through its course, it was like a ship on the horizon and you would see it and if you watch, it’s static, it’s only when you turn away and come back a year later that it’s moved or gone or whatever, and that was fine. He also informed me the medication was very good and very powerful, albeit that it had a finite application duration as it were, and that was fine, I understood that. And he assured me that potential cures were around the corner, the research was well funded, well advanced, and there’s a lot of interest in science taking place. Now that was all fine...’

Rory's extensive use of *'that was fine'* reminds me of Arthur Frank's comments following observation of a cancer support group, attended mainly by people in remission, whose opening ritual usually involved each person concluding their brief weekly update with 'I'm fine!' To Frank, 'I'm fine' in the context of the group expresses a preference for restitution stories and a 'discomfort at hearing illness told in other narratives.' Whilst this preference reflects a 'natural' desire to get well and stay well, 'people learn this narrative from institutional stories that model how illness *is to be told*' (Frank 1995, p.78).

'That's fine' in the context of Rory's interview, expresses an acknowledgement of this narrative preference and the fact that, from the moment of diagnosis, he receives strong guidance on how his illness story should be told. It is reminiscent of Jutel's aforementioned metaphor in which she suggests that 'receiving a diagnosis is like being handed a road map in the middle of a forest. It shows the way – but not necessarily the way out' (Jutel 2011, p.1). In Rory's case, not only has he been handed a map showing the way, but he has actually been told that, in the future, there should - even will - be a way out. He has been encouraged to aspire to a restitution narrative.

Such assurances of *'potential cures around the corner'* are doubtless well-intentioned, aimed at giving comfort and sustaining hope, as is the assurance that Parkinson's is one of the more benevolent (or benign) neurological conditions. However, to be told this is to be faced with a 'hierarchical ordering of [neurological] conditions' (Pinder 1992a, p.8) that, alongside the desire for restitution, may crowd out – or stifle – the patient's narrative. It is perhaps not surprising, then, that Rory, even when faced with adversity, comments *'that's fine.'*

Adversity comes in many forms, one of which directly challenges his neurologist's assurances. Having described how 'googling' symptoms prior to diagnosis caused alarm, it emerges that googling Parkinson's after diagnosis also produces 'some alarming moments.' In addition, he is given access to a research paper (not usually accessible to the general public) on the benefits of exercise, the abstract of which Rory remembers in the following words:

‘Exercise has proved to be tremendously beneficial. Of the 17 patients who had been undertaking the trials on exercise, it’s produced tremendous results. Several of them can now stand on their own and [have] even been able to go up on their toes while standing.’

In a totally matter of fact, unemotional way, he says:

‘That wasn’t really what I wanted to read. But you know, so be it, that’s fine.’

Clearly it is not fine. It is *‘alarming’* and it is not what he wanted to read, but the narrative force at the time of his diagnosis has left him ‘drawing from discourses of acceptance’ (Speed 2011) and not resisting or problematizing his medical encounter. He has done as he is told – he even explains how he approaches information finding on the internet, again placing the responsibility on himself:

‘To tell the truth, that’s just qualitative sifting of the material and that’s fine, you know, I should be able to do that.’

‘But reliability is not, of course, the only benchmark required in seeking out information and this time Rory’s voice hints at the irony of the situation in which he finds himself as he reflects further on the research paper about exercise:

‘What’s more alarming is, is accidentally stumbling over something you didn’t want to know about the disease as opposed to something you do want to know. So suddenly finding that, you know, exercise benefited the 17 patients doing exercise to the point that one could stand up wasn’t something I especially wanted to read, but it was a reliable source!’

Rory is not alone in experiencing such pitfalls when seeking out information about his new diagnosis, as can be seen from the comments made by several other participants in this study (table 15 below).

Janie: ‘And that weekend I was in the local bookshop and I bought a book, it’s still down there, and of course it goes through everything from hallucinations to – because you don’t know enough. In that time you’re there, they don’t really tell you very much about what that means, you know, you’ve heard the name... It was before the days of having the computer and Google, I sort of bought, as I said, I

bought that book and I flicked through it, went and had a coffee and flicked through it in the town and I thought, ‘Oh my God,’ all these things came up, you know, ‘I can’t be doing with this.’ I actually put the book away for quite a long time!’

Michael: So I went to the GP. And he said to me, ‘*I think you’ve got Parkinson’s disease. How do you feel about that?*’ I said, ‘I’ve heard of it, and I don’t know anything about it.’ And he said, ‘*Go and buy a book.*’ And I was out of the surgery and diddlyquat, and I went and bought the book on the way out. And I got to page 7 and forget it, there was this line drawing of a scrunched up man with a walking stick. And only having scanned the initial pages of this book I thought I’d reached.... and I shut the book and I didn’t open it again for another seven years.

Joan: ‘That’s reminded me, when I was making my initial enquiries online, you know, it was very matter of fact and quite brutal really, the description of symptoms and developments, to the extent I haven’t looked at it since actually.’

Sheila: ‘But basically I was given some leaflets to read and that, that was it you know, and to go back in to see him in I think it was about a month’s time. I’d obviously sort of looked here and there into it and knew that it was progressive, wouldn’t get better and, actually some things are quite, well, exceedingly frightening when you look into it, if you look into it deeply enough... And I don’t think they give everybody the information, you know the true information about how it can be...not for quite some time, a long time actually, unless you look into it yourself... I think they sort of fob you off actually... and for some people that might be good and for some others I don’t think it is. I think there’s um, it’s hidden – there’s a lot of hidden stuff about it that you aren’t told. I still think that now actually, you know ...they don’t want to frighten you which, you know, is good, but, umm, personally I would like to know, you know I think it’s only fair to know...what’s possible.’

Table 16 Voices of other participants on seeking information about Parkinson's

6.4.3 ‘So I guess I’m a control Parky’

Importantly, as well as being the only participant to have been assured at diagnosis of potential cures around the corner, Rory is also the only participant to have been actively involved in a clinical trial at the time of his interview, although disappointingly only as a ‘*control Parky*’ due to his not meeting all the criteria set by the project. Intriguingly, his narrative about medical research remains purely

descriptive and, in contrast to other participants, does not enter into discussion about its merits or its likely outcomes. In line with Frank's 'Quest Memoir' type, involvement with medical research suggests a degree of stoicism ('that's fine') along with an acceptance and incorporation of the illness into his life.

However, it is in talking about another piece of research in which he and his wife were to have participated (aimed at eliciting couples' responses to the diagnosis) that he reveals how difficult it can be to maintain a congruent approach to the illness of one person within a relationship. The illness narrative is not only his to tell. How he negotiates his illness is contingent on others' reactions, not least those of his wife.

Thus, she is frequently asked how Rory is, how he's doing, how he's coping '*but nobody ever asks her the [same] simple question.*' He therefore '*thought it would be great if she gave voice to that concern through a research project.*' However, '*in doing so, you also make everything much more concrete.*' As Frank suggests, 'life is effectively invisible until a story makes that life narratable' (Frank 2010, p.75).

Rory's wife is not ready for the story that makes their life 'narratable'. The story that she has to tell is not the story she wants to tell: invisibility is preferable. Rather poignantly, Rory says:

'Burying her head in the sand **while things are good** is a valid defence strategy for her. That's fine and it's working. So to bring it all out and think about the future and what it will hold isn't. So we stepped back from that one.'

At this point of the interpretive process I find myself reflecting on Frank's comment that there is often a tension between interpretation and story since 'the need for interpretation implies something concealed or left unsaid in the story, that interpretation must clarify or fill in, but then stories mock interpretation for saying less than the story conveys in the sum of its effects' (Frank 2010, p.87). As I listen again to Rory's words I am as deeply affected by them as I was at the time of the interview, and although the sum of their effects may be greater than I am able to convey in my interpretation, I feel I owe it to Rory to take the risk of expanding on what, at this point, he does leave unsaid.

Unspoken are the parallels between the purpose of the research from which they have '*stepped back*' as a couple and the purpose of my research in which he is

involved on his own. By participating in this study, Rory implicitly acknowledges that, even if his wife prefers to *'bury her head in the sand,'* he is ready to give voice to his experience, in full awareness that this may *'make everything much more concrete.'* His response to his illness is clearly mediated in part by concern for his wife and what she is able to bear, and this is perhaps the strongest indication in his story that he feels compelled to live a 'life as normal' narrative – the narrative that *'declines to share illness experience...in order to preserve other experiences.'* It is the story that *'continues to unfold but. ...seeks to minimise illness'*(Frank 2013, p.194).

Arthur Frank is very suspicious of this narrative type – indeed, he omitted it from *The Wounded Storyteller* because he felt it perpetuates silences, doing little to *'spread the concentric circles of witnessing suffering'* (ibid. p.195) and suggested that the risk of this type of narrative is that *'the healthy people around the ill person are choosing to treat their lives as normal, and the ill person is subtly (or not) coerced into accommodating their anxieties'* (ibid. p.196).

I would argue that it is precisely *because* Rory has felt the necessity to minimise his illness that his story should be heard. Not to give voice to his narrative would perpetuate silence not only about his illness, but also about the social and cultural forces shaping his response to his illness. Writing over thirty years ago, Anne Hawkins suggested that *'the expectation of our culture is not only that the sick will continue to function as best and as long as they can (modern pharmacology helps to make this possible) but that their illness will serve as an opportunity for bravery and heroism.'*³ Rory's narrative illustrates how strong this social and cultural expectation still is; how it seeks him out from all quarters^a and therefore part of the interest of Rory's story lies in the tension that emerges as he tries to *'hold his own'* (Frank 2010).

At times it is as though he has no alternative but to declare that the difficulties confronting him are 'fine' in the face of a medical narrative that plays down the serious nature of his condition and a social unease with illness that results in people feeling *'compelled to provide answers and hope'*(Nettleton, Watt et al. 2005, p.207).

^a From his interview I would suggest that subtle pressure to minimise his illness experience comes from: his neurologist, his family, his workplace, friends and acquaintances as well as the internet.

Thus he is told by friends: *'Oh yes, don't worry about that (i.e. Parkinson's), my neighbour has had it for X years and he's fine, still cycles down to the beach hut for swimming on Sundays'* or people on the web who try to *'convince'* him to see it as *'a change to be embraced and celebrated.'* And yet, through reading research papers he is aware of the possibility of another, more fearful narrative that could unfold, and this information is reinforced by meeting someone of his age who, after a number of years with Parkinson's *'was frightening. He's got severe dyskinesia and terrible movement problems.'*

6.4.4 'Holding my end up'

It is important to emphasise that Rory's interview took place in his workplace and it had to be cut short in order for him to attend a meeting. Although shorter than my other interviews, by the time we finished I nevertheless felt that Rory had told me what was important to him at the stage of disease progression he had reached. He was still holding down a full time job and, in his words, *'a couple of colleagues do know, and most do not.'* It was clearly important to him that, but for a couple of days off since diagnosis – one being the day after when he had been *'thrown into panic'* – he had not missed a day's work in two years - *'so I think I'm holding my end up from that perspective.'* He was also *'holding his end up'* physically, stating at the beginning of the interview that *'my, my weapon of choice has been exercise'* and ending his interview 45 minutes later by expanding on this:

'As I say I have a lot of exercise, do 4 to 5 hours a week, it's sort of, if nothing else, it gives you the confidence that you can do something physical.'

Indeed, physical exercise gives him the chance to measure himself against others and at the end of the interview he recaps, saying:

'Well, you want to know, right, you know, if [a fellow gym member] can do it in just under two minutes, I want to do it in just under two minutes and I can, so that's fine. You see what I mean? It gives you the confidence that physically you're still in there.'

In hindsight I am pleased that we ended the interview on this positive note. Nevertheless, there is a striking vulnerability within this narrative that cannot be ignored. Just beneath the surface bubbles a thread of anxiety that is constantly

looking towards the future and it is clear from many of Rory's comments that he knows his future does not involve restitution. For the time being, his determination to keep as physically fit as possible helps him tell a 'life as normal' narrative, but I sense that he is only too aware that 'when restitution does not happen, other stories have to be prepared' (Frank 2005, p.94).

A danger is that the life as normal narrative, like restitution, may prevent people from 'developing a different identity of self,' something that Smith and Sparkes recognised as 'the unhealthy side of narrative' (2004, p.625). Rory is arguably deferring the development of a new identity, and even when talking about the drugs he is taking, he is keen to emphasise that:

'I feel fine, I don't look too Parky; I assume it [drug] is having a beneficial impact.'

He is, however, anxious about the future, as he recognises that

'It is having an impact on my work and on my professional life after two years. And that worries me, you know. There's still X number of years to pay on the mortgage and it's worrying to think that your professional career might be cut short.'

Whilst the physical confidence may be there, the anxieties stem from the less immediately visible aspects of Parkinson's and, as he talks about work, his narrative outlines a series of gradual losses: an overall loss of confidence at work; a loss of confidence in asserting his point of view stemming, possibly, from a loss of timing and a loss of interest in the 'minutiae' of technical information:

'There's a vigorous conversation going on and trying to find the right point to cut in with your point, for some reason is really quite difficult now.'

He has lost the ability to type – *'to be fair it wasn't great initially, but now it's a lot worse'* and he is anxious about his voice:

'I worry about the, my voice becoming less clear because I've always had a deep and wooden voice but, you know, every time now somebody says *'Sorry, I didn't catch that,'* you sort of stand back and think, 'Oh yes, ok, my voice really is going, that's the third time he's asked in the hour.' So you do worry about that.'

A number of other participants also reflect on changes in their voices:

Charles: ‘My speech is a little affected I’m afraid, just, not have quite the clarity it used to have.’

Henry: ‘And in the last six months to a year, it’s become much more apparent, not only to me, but also to others, both in terms of tremor, in terms of voice quality, both in terms of sometimes slurring words and also the actual strength of the voice as well, and I’ve come to a point where I am much more likely to tell people up front, to save any embarrassment that they may have, and to clarify exactly what symptoms they can look for.’

Angela: ‘And I find my speech goes now, which it didn’t [...] I get quieter. I get told off, to speak up, speak up. When I get tired it’s almost I can’t, you know, I just can’t bring myself to... And also articulating somehow, I slur a bit, you know...starts to get, it’s just like the muscles just say, ‘I can’t be bothered anymore.’

Derek: ‘Oh and I had speech therapy as well. I did an intensive course of speech therapy. That was an hour a day, four days a week for four weeks [...] That was quite demanding but I feel it was worthwhile at the time because my voice level went up half a DB, which doesn’t sound much, that’s a decibel sorry. That doesn’t sound much but is quite a lot in the range we were talking about.’

Jonathan: ‘And I’m, at the moment, doing voice therapy [...] Which is quite – but, you see I’m conscious that I used to have a voice that was fairly strong and which would show depth of meaning in your voice. And I was afraid that my voice was becoming quieter and I couldn’t show irony or anything like that in my voice’ [...]

Janie: ‘Yes, people have said that my voice has got very quiet, and I’ve found people ignoring me. I’m saying something and because you’re in a group, and I called somebody downstairs this morning, I thought I was shouting quite loudly, but she didn’t hear me.’

Kay: ‘But yes there’s a few girls in my group that have got quite soft voices, and a few of the chaps. And it’s quite hard. So when we go out we have to go somewhere where...isn’t too bad [...] Some pubs have different acoustics [...] so we have to watch where we go really. And the very first night, I was struggling to hear what one of them was saying. It’s difficult because I know the trouble she’s having but I still needed to say ‘pardon.’ And she said, ‘*I can’t talk any louder.*’ And I said, ‘Yes I know.’ But I couldn’t hear her. That’s awful really. So yes don’t really relish that happening, not being able to communicate.’

Table 17 Participants' views on the effects of Parkinson's on their voices and speech

Rory talks about loss of sleep, loss of co-ordination, loss of posture – ‘*I have the leaning Tower of Pisa look occasionally*’ – and, the one that puzzles him most, a loss of time:

‘I don’t know if this is something that other people have spoken about.^b So they speak about freezing and it’s obviously much more noticeable with people with advanced Parkinson’s. But certainly there are occasions where you have just stopped. You know, you put on your socks in the morning and you suddenly realise that you’ve been sat there for ten seconds not really doing anything, just gazing out through the window.’

Perhaps because we are in the workplace it is noticeable that Rory, having described the loss of time in a domestic situation, then questions how it may be affecting him in the workplace:

‘And while you think, yes, you’re just mulling things over in your mind, actually those instances might be quite common, so you wonder about your efficiency at work. Now, I don’t know if that’s something other people experience.’

Anyone reading my transcript will see that I made no attempt to reassure Rory that yes, some other participants had referred to a sense of losing time, as well as questioning their efficacy in the workplace. Seeing this in black and white evokes a sense of guilt at what appears to be the selfish nature of the research interview, apparently focusing solely on eliciting ‘data’ for my study. However, as I listen again to the interview, the reality is that Rory phrased these questions rhetorically, leaving no space or time for me to offer up any such examples even had I thought it appropriate to do so. It is, therefore, a useful reminder that, in undertaking analysis, it is important to re-read transcripts in conjunction with listening again to participants’ voices; hearing the inflections, the emphases, the pauses and the emotion – aspects of an interview that are easy to overlook as time elapses and more and more interviews undertaken.

Despite the rhetorical nature of Rory’s questioning, it feels appropriate to put his voice into dialogue with other participants whose experience resonates with his own:

^b i.e. other participants in the study

Jay, whom I also interviewed in the work place, often referred to work as he described the effects of Parkinson's on him: 'I was slowing right up, you know, I couldn't work out why I couldn't get the jobs of the day done. I seemed to be sort of ... the thinking process wasn't working properly. Jobs which should have taken me minutes were taking me, what I thought were minutes, but were tens of minutes.' A little later in the interview he again explains: 'Well I got very slow, I think a general slowness in the sort of, if somebody asked you a question, they would think you hadn't heard it, because I was like, there was like a delay before they got a response. Didn't realise that. But I suppose it was just the general brain had slowed down. I thought perhaps it was just a general, like, lethargy.'

Philip, who had always worked in the outdoors, also expressed similar difficulties as he tries to keep some work going: 'And I'm not able to keep up with the guy I'm working with. Luckily he likes to work on his own and I have been pottering around, you know, assisting sort of thing, with bits and pieces, but I find myself turning round and thinking what the heck am I doing, where am I going now? You know, so I get distracted very easily and one job sort of takes longer than ever. And I do other little jobs in between and I can't keep myself concentrated. It's, you know, something that I've been very busy and always applied myself as hard as I can to everything. It's now a case that I can do so much and then I have to sort of change tack to freshen me up sort of thing.'

For **Kay**, her initial response was not to tell anyone about her diagnosis other than her manager: 'I just felt I didn't want people to treat me differently.' But 'it's difficult being at work now because I feel like I'm not as effective as I used to be, so therefore I feel quite bad.' I later learn that the pressure of concealment became too much and she gradually told her colleagues. Even so, 'I always get the impression that they think that now I'm a lightweight, because I don't volunteer for everything because I just think I'm not going to manage it. I am bringing work home to catch up. I do forget to do things and forget things when I'm asked questions. And you need to be on the ball really and I don't think I am any more. So I've started to think about when I'll have to give up work. And the shame of it is that when I finally give up work I'll go out on a low, not a high. And you end up giving work up in the end because you can't do your job, which is a terrible reason to give up a job. And so you leave really, not because you want to, but because you're pushed.'

Janie, too, found that she became less effective and felt support draining away: ‘So...it was gradually I was unable to do less and less and I was just getting so tired and that is quite draining when you’re not 100% yourself. So I carried on working... and gradually, as I said, I was off a couple of days here, a couple of days there. The manager wasn’t particularly happy; I didn’t feel she was being very supportive. She used to clock me in, we had sort of flexi time, I used to get to work at half past eight and leave at half past four with half an hour’s lunch, which works out the hours I should have done. But she always seemed to, when I was going at half past four, she always seemed to be milling about, ‘*Oh are you off already?*’ and I was thinking, ‘I’ve tried to work and do my best with what I’ve got.’ And that didn’t help in a way. Eventually I was signed off with depression. Yes, I was off, I was signed off, and gradually I kept going back to the doctor and he signed me off a bit more and a bit more. So eventually I just recognised that I wasn’t going back.’

Sheila, having lost her job following her diagnosis, ‘looked for a part time job and got a job as a receptionist at [...] and I stayed there for 18 months, and it was during that time the symptoms got worse...umm...you know, much stiffer, much slower, umm...very, very tired and in fact I can remember just one day sort of coming home, getting in the bath and not being able to get out again.... And it got to the stage where I could either go to work and not do any housework, or do housework and not go to work...so I decided I had to stop working, you know...’

Table 18 Participants' views on the effects of Parkinson's on their ability to work

6.4.5 ‘Who is making the claim of normality about whose life?’

Before leaving Rory’s story, it feels important to offer a brief narrative account from another interview. In Frank’s view ‘claims (i.e. about normality) express a desire to live well with illness, although it still matters *who is making the claim of normality about whose life*’ (emphasis added). He has learned to respect silences, but he has not lost his ‘suspicion of what might be sustaining them and what their cost can be’ (Frank 2013, p.197). In contrast to Rory’s situation where his wife is not ready for the story that makes their life ‘narratable,’ my interview with Henry offered the obverse when, in an interesting twist, his wife joined us halfway through his interview.

Up until that point, Henry had made light of his illness, choosing to read me a number of wonderfully funny, light-hearted poems that he had written. However, he invited his wife to join us and in so doing allowed her voice to comment on, and even change, his narrative. Taking part in the interview enabled her to express how difficult it can be to live with someone who determines on the path of maintaining normality. Here she describes her husband's insistence on living a 'life as normal' narrative following diagnosis:

'Yes I mean it has to be obviously set against the sort of person Henry is, you know, and I've known him for fifty years. I say 'known him,' as much as you can ever know anybody. And so when he was first diagnosed, I mean Henry was doing quite a high level job. And I think there was an element of denial there that, although Henry was aware that, you know, he was going to get worse and how much worse was it going to get, you tried very, Henry tried very hard to keep going and pretend it wasn't there, which, for the family, was actually not as easy as if he'd sat down with us all and said 'Well look I've got Parkinson's disease, this may happen, this may happen.' And we'd just all have to deal with it. But there was nothing like that. It was just almost not talked about by Henry. But the rest of us did. Now that's the sort of person Henry is anyway. So, you know, I remember his mother telling me that when he went to the dentist and his brother as well, Henry would always sit there looking pale, sort of with his teeth gritted and his brother would be making a big fuss. You know, Henry is somebody who internalises and perhaps denies situations to some extent. So that, I think, has been the most difficult, for the family and for me, thing to deal with. Henry's constant, 'Oh everything is fine.' Well actually it's not! And as it's got progress – progresses, obviously that element has to be sort of addressed at some point. And that's what I've been trying to do over the last probably 12 to 18 months. And I think you've realised that when you've seen yourself on video and things like that, or pictures of yourself, you think 'Golly is that really me?' I don't want to paint a horrible picture.'

Table 19 'Who is making the claim of normality about whose life?'

Henry does not dispute his wife's suggestion that it was he who declined to share his illness experience in the first few years following diagnosis and although this may have been done with the best of intention, it certainly begs the question 'at what cost?' If it was to 'preserve other experiences' and prevent relationships changing, it has, according to his wife, misfired and her narrative account seems to support Frank's assertion that the danger of preserving normality lies in the fact that it 'shuts down storytelling' (ibid. p.194).

6.5 Keith

“The illness story faces a dual task. The narrative attempts to restore an order that the interruption fragmented, but it must also tell the truth that interruptions will continue.”

The Wounded Storyteller (1995, p.59)

Keith was diagnosed with Parkinson’s in his late twenties, and had been living with the disease for almost eighteen years when I met him. I have chosen to include Keith’s voice in this study not only because it speaks strongly to my original research interest (medical research) but also because his narrative so ably lends its voice to reflecting on one of DNA’s ‘crucial questions’: How the storyteller ‘holds his own’ in the act of storytelling. Throughout this interview, and particularly when talking about medical research, it becomes apparent just how important – and yet how difficult – it is to ‘sustain the value of one’s self or identity in response to whatever threatens to diminish that self or identity’ (Frank 2012, p.33).

6.5.1 ‘You’ve just gotta not fight it, just accommodate it.’

My interview with Keith was interrupted even before it began. The following extract from my field notes reads:

As we began, Keith had an attack of dyskinesia. This can be heard at times through considerable pauses in speech as well as his voice dipping in and out. The attack took the form of uncontrollable body movements causing considerable difficulty in staying on his chair. However, he wanted to carry on. It clearly meant that talking took more energy than had he not been experiencing dyskinesia and it is noticeable that the amount said in the course of an hour plus interview is considerably less (word count) than other participants interviewed for approximately the same amount of time but not affected by dyskinesia.

Looking back at my notes, I wonder about my use of the word ‘attack.’ Maybe I used it because Keith’s dyskinesia had a particular and sudden force behind it, or maybe I had subconsciously absorbed Keith’s use of military metaphor during the course of his interview. Having lived with Parkinson’s for nearly twenty years, he wanted me to understand that:

‘You’ve just gotta not fight it, just accommodate it.’ On the other hand, ‘Every day you get a little victory – and they all merge into one big war. You just look for the victories every day.’

More importantly, his dyskinesia provided a powerful visual metaphor for the ‘perpetual interruption’ that disease and illness may introduce into a person’s life (Frank 1995, p.56). In this case it is, of course, the diagnosis of Parkinson’s - a ‘*degenerative, incurable, lifelong disease...three things you don’t really want to hear.*’ Hearing his neurologist’s voice merge with his own as he struggles to stay on his chair renders even more poignant his comment that, on learning that he had Young Onset Parkinson’s, he draws on the one story he knows: ‘*Your first thought is, sat in a wheelchair, in a corner. I’m a seventy year old bloke, shaking like a leaf.*’ Diagnosis projects him into an uncomfortable and uncertain future forty years hence.

In paying close attention to how Keith talks about medical research, it is possible to see how hard his narrative works at ‘constructing [an] ordered account from the chaos of internal experience’ (Josselson 2011, p.226). As we talk, he is able to look back and reflect that, although he disclosed his diagnosis to others, he believes that for nearly a decade ‘*I was in denial.*’ Disclosure to colleagues was immediate – ‘*What’s the point in hiding it?*’ The denial, he explains, was ‘*internal*’ as a consequence of which he ‘*didn’t want to know about, anything about it....Not interested in research, not interested...*’ Denial was, in part, made possible by medication. With a considerable sigh he recalls that:

‘I wasn’t that bad then, just the odd tremor and the dragging of the leg. The medication seemed to cure it...it **seemed** to cure, to cure the symptoms anyway...which is all well and good.’

The ‘but’ in his story is silent yet palpable. It is made audible through two uncomfortable aspects of his story: the breakdown of his marriage a few years after diagnosis – ‘*It was too much to ask for anybody to cope with and the lack of knowledge [back then] compared to now...*’ and the fact that after a few years the drugs which had seemed to cure it ‘*stopped working.*’ In a heart-stopping moment he says – ‘*they were giving me dyskinesia like I’m having now.*’ Recalling that

period of his illness experience seems to increase the intensity of his dyskinesia, and I interrupt, saying ‘Do say if you want a break.’ But he needs to continue. It is as though not to continue would allow time to acknowledge an uneasy parallel between his past ‘dysfunctional’ dyskinetic self and his present ‘functioning’ dyskinetic self. As the dyskinesia threatens nausea I once more ask him whether he would like water or to take a break. He politely cautions me with:

‘No, I’m fine. Honestly. And it’s empathy that you’ve shown me today, that’s what we require at some stage, but not too much.’

6.5.2 ‘It’s a big thing, a brain operation’

It is Keith who brings up the topic of his involvement in a Deep Brain Stimulation trial. He talks to me about it in considerable detail and with considerable pride. *‘It’s a big thing, a brain operation,’* but for Keith *‘it’s been a terrific success.’* Indeed, *‘I’ve never looked back since.’* It is at this point that I sense he is enacting a story about himself in which ‘illness is the occasion of a journey that becomes a quest’ (Frank 1995, p.115). It is as though, having suffered ‘loss of self’ (Charmaz 1983, p.168) he is now able to reconstitute his identity (Charmaz 1987, p.318).

Of all the participants in this study who frame their current understanding of self in terms of a quest narrative, Keith’s is the voice that speaks most strongly to Frank’s ‘quest automythology’ type, suggesting a survivor who is ‘reborn’ and acquires a new identity through self-reinvention. He makes sense of years of denial by saying that

‘It’s terrible looking back’ but ‘at the time it was right for me – I would not be who I am without going through the denial first.’

The person to emerge from this denial is accepting of his illness:

‘It is part of me now. It’s not something I’ve attached to me. It is me, I do have Parkinson’s.’

He has undergone ‘individual change’ and is now a ‘better’ person. Prior to diagnosis he was a *‘bigoted, homophobic, racist idiot’* as well as someone who

found it *'hard... to show my feelings and emotions.'* Parkinson's has *'enabled me to do that'* as well as *'look past people's first impressions.'*

Sustaining this change is, of course, Deep Brain Stimulation. It is the latter that rescues him from becoming a *'vegetable... because, just, I was on 38 tablets a day.... and now I'm on 5.'* The success of DBS is such that, although he has lost co-ordination (swimming) and rhythm (dancing) it has enabled him to gain other skills (riding a bike, kayaking). Indeed, he has gone from relying on a *'walker'* to being able to walk unaided, albeit not long distances. DBS has restored a degree of order to the chaos that has been his illness experience. For Keith, the decision was a *'no brainer:'*

'It's not brave. You either carry on with 38 tablets a day, not knowing what... it's going to do to you in the future with your liver and your kidneys and goodness knows what else (speech very slurred) or ... you take the option.'

6.5.3 'Have you been drinking?'

I sense a real energy emanating from Keith as he engages in talk about Deep Brain Stimulation. Nevertheless, his words suggest that he has had to learn to resist the narrative force of 'restitution' and, in what sounds a little like a mantra, he reminds me that DBS is:

'Not a cure, it's only an aid' and 'if you treat it as a cure you'll be disappointed. It's only...there is no cure at the moment.'

The enactment of his illness story in terms of quest automythology appears to give him some protection from other disappointments. Early in his narrative Keith implies that times have moved on since he was first diagnosed; there is considerably more knowledge about Parkinson's now, and back then *'it was like a stigma.'*

This suggestion of stigma as a thing of the past is contradicted when, in a recent early morning visit to the dentist, he is asked 'Have you been drinking?' Listening again to the interview reminds me that, at the time, I was astonished that he would be asked this by a health professional:

J: And it was a serious question?

K: It was serious

J: It wasn't because he knows you (i.e. I was suggesting he may have been joking with Keith)

K: No, no definitely, honest, *'Have you been drinking?'*

J: How did you respond?

K: I just said 'Naa', I said 'I've got Parkinson's.

In my synopsis of Keith's interview, I wrote:

For me, a dentist asking him 'Have you been drinking?' seems astonishing, bringing to the fore questions around identity, stigma and labelling. It is as though the dentist holds up a metaphorical mirror to Keith and his condition – there is no escaping from it.

For Keith, the purpose of relating this episode is less to illustrate the stigma still attached to Parkinson's and more to show me the degree to which his experience of Parkinson's has changed him for the better: *'Years ago I'd have lost my temper and just gone mad at him.'* He is now able to modify his reaction in part because he is able to stand outside himself and see that *'it [the way he walks] must look bloody funny. I mean – it feels awful, but to outsiders it must look dead funny,'* and in part because he knows that his pre-Parkinson's self *'would possibly have said the same thing.'* Parkinson's has *'enhanced my life – and given me a vision of being able to see disabled people as people.'* He now understands others better as he has become *'one of the minority looking out at the majority.'*

I note that the energy expressed when talking about DBS evaporates as I ask him about his attitude towards medical research more generally. He explains that it makes him *'scared, apprehensive of any false leads.'* It is as though to talk about medical research, despite his having been involved in it through his DBS trial, is to threaten his present, precarious situation; to threaten who he is and who he has become by introducing thoughts of what he may become in the future: *'I'd be so scared now, after having such a big operation, that it (i.e. any other intervention) could fail.'* Talking about medical research interrupts his narrative flow and is

paralleled by an actual break in the interview while he responds to the high-pitched beep emanating from his electronic pillbox.

6.5.4 'A continuous wave'

On resuming the interview I sense his neurologist's or nurse's voice entering the dialogue as he explains, with renewed enthusiasm, the purpose of the different coloured tablets on the table in front of us:

'What you're actually looking for is a continuous wave. You're going to get some fluctuations obviously, but you try and avoid the peaks and troughs of, like, stormy seas shall we say.'

This description seems a perfect metaphor for his presentation of self. The continuous wave is the fact that:

'You've got Parkinson's. It's not going to go away. It is lifelong; it is degenerative; it is incurable. (Pause). That sounds easy now, but accept it, because, because with acceptance comes relief ... and relaxation. And you just... just go through life. I've never ever been happier.'

There are, however, fluctuations that take him 'off piste' occasionally. However much he feels he has become a changed person, successful negotiation of the illness experience is contingent on the reaction of others and he still finds that *'I apologise to everybody and tell them I've got Parkinson's.'* This is something *'I've got to stop.'*

The seas become stormier when he recalls that the embarrassment caused by Parkinson's results in stress and *'the worst thing of all'* – loss of dignity. Falling over in a supermarket and being helped up *'by a little old lady of about 86'* is *'not good,'* but more serious is the fact that the darker side of Parkinson's symbolised by this embarrassment, stress and loss of dignity, means that he cannot live with his new partner. He needs his own space and has to *'be selfish to keep going.'*

6.5.5 ‘You die with it, not of it’

Whilst talking about DBS is energising and liberating - it has given him the ability to live the life he currently enjoys – talking in the abstract about medical research is to be forced to confront the peaks and troughs of a life where his DBS may no longer work. Instead of pursuing this disturbing thought, he seeks solace in his drugs (outlined above) and in the circulating Parkinson’s narrative that ‘*you die with it, not of it.*’

Of course, the boundaries of this narrative are fluid and although he prefers to try and stay with the ‘continuous wave’ provided by being ‘*happy with today. What happens tomorrow happens tomorrow,*’ the fact that he has spoken of a ‘tomorrow’ introduces suspense and again interrupts the narrative flow. Vehemently, he states that:

‘I’ll never be, I will never, ever go into a home. I know that. That, that is the one thing... the day I can’t wipe my own backside is...’

His voice fades away before returning with thoughts of going to Switzerland.

‘Yeah. We ought to be given the choice. When you’ve tried so many different things...it’s the only thing...there’s too many people living too long. Sounds a bit peculiar, but –it’s quality of life. I would hate to be sat in a ruddy... chair for 18 hours out of 24... Can’t move, stagnating, smelling...can’t even wash your hair. I do like, I do like to look presentable, look nice. I’d hate that. I am a control freak.’

Keith’s unflinching evocation of his possible future, vividly illustrates Toombs’ assertion that ‘advances in medical technology [...] increase the patient’s perception of loss of control’ (1995a). In what may seem an uncanny reference to Keith’s situation, she further asserts that ‘we find ourselves terrified not only by medicine’s impotence to cure our disease but also by medicine’s power to keep us alive.’⁴ Furthermore, although Keith worries that his views on longevity may sound a bit ‘*peculiar*’ it is clear that one factor fuelling the legalised dying debate is the premise that ‘the option of assisted suicide can provide some sense of control over a desperately threatening future’ since ‘what patients fear most is not death itself but rather a process of dying (or living) that robs them of dignity and personal integrity’ (ibid.).

Just as Josselson states that any account constructed by a narrator is ‘never a single self-representation’ (Josselson 2011, p.226) so Frank emphasises the open nature of any one person’s illness story (Frank 2010, pp.119 & 182). This is apparent in Keith’s story, the fabric of which bursts with different threads, illustrating narrative complexity, in part due to ‘changes in storytelling [that] occur over time’ (ibid. p.119). In the context of this interview, Keith is keen to present himself as someone who has gained something special from his experience and is ‘living successfully’ with his illness – both at the individual level by becoming a ‘better person’ (Quest automythology) as well as using his experience for the betterment of others (Quest manifesto). Thus, there is a purpose to everything and the denial he has been through enables him to understand:

‘why people [with Parkinson’s] are suffering, why people are so downthat you need to accept it. You really do need to. My advice to anybody with, speak to somebody with the problem first. We’ve just set up a peer support group where... if somebody’s got a problem they’ve got somebody to speak to with Parkinson’s.’

Perhaps not surprisingly, he prefers not to dwell on the more difficult aspects of his illness experience – the depression which he mentions in passing (*I have suffered from depression for years, but I take a little, little happy tablet now, but whether it’s a pl, pl, er placebo or not I don’t know*); the apathy that he clearly ‘suffers’ from at times (*Apathy is a terrible thing ... You can just sit there and just wallow. I do do that occasionally, I must admit that*), and the day to day difficulties of living in an unreliable body that may ‘freeze’ (*if I do a big shop, I have to, I have to have somebody with me... in case I freeze.... like can’t move*) or go into waves of uncontrollable movement, as during the interview.

Frank suggests that ‘naming types of narrative can authorise the telling of particular stories and [...] can liberate people from stories they no longer want to tell’ (Frank 2010, p.119). Just such a process seems to have taken place during Keith’s interview, even without the overt ‘naming’ of narrative types. It acts as a conduit for making sense of his illness experience, as well as his changing response to it over the many years since diagnosis and after the interview Keith expresses surprise at how long he has spoken - largely unprompted - before reflecting on the fact that the interview felt ‘cleansing.’

6.6 Sarah

I have chosen to tell Sarah's story in part because it is so different from Keith's. Unlike Keith, I do not sense that Sarah is liberated from a story she no longer wants to tell. Rather, she remains trapped in it. At the same time the interview enables her to name and shame Parkinson's and give voice to a story that has otherwise been silenced.

6.6.1 'It doesn't cost anything to be nice, does it?'

It was almost exactly halfway through Sarah's interview when something quite extraordinary happened. Sarah, after a deep exhalation, commented that I hadn't yet had a biscuit. Absolutely truthfully I started to answer that no, I hadn't, but 'I'm all ears, you see, and I can't do two things at...' I was about to say 'once' when she interrupted with a comment that led to one of the most poignant moments I experienced during the course of my research.

S: 'I can't imagine **why** someone would be interested in Parkinson's. Why did you pick Parkinson's?' (She said this with not a hint of resentment in her voice, just incredulity.)

J: Well, I didn't pick it....

S: It picked you

J: Well it picked me

S: It does that!

She laughed, but for me it was a striking exchange for two reasons. First, her surprise that anyone should be interested in Parkinson's is surely an indictment of her experience of living with a Parkinson's diagnosis for 14 years, reflecting a broader societal – and medical – issue, noticed and remarked upon by some other participants. Whilst no one else I interviewed said, in such direct terms, '*I can't imagine why someone would be interested in Parkinson's*' some did comment on a circular problem in which a lack of interest and understanding feed into each other (Table 19 below).

Caitlin, for example, refers to Parkinson's as a 'Cinderella' condition, whilst **Keith**, in slightly hushed tones, admits that 'I feel jealous sometimes – of people with cancer,' explaining that society seems not only to know so much more about cancer, but also to be so much more interested in it. Parkinson's, he concludes, 'is not sexy.' **Angela** asks to be referred to a local consultant whom she understands is 'interested in Parkinson's, whereas it was very clear that the one that I saw at Y- it [Parkinson's] obviously wasn't one of his interesting ones!' **Ted**, himself a retired health professional, feels that 'even GPs' don't understand much about Parkinson's [...] Well [in] my experience, the way they talk to you, the way they, you know, the way they say things ... You know, 'you should be OK, you'll be fine with this...'

Barbara, from the perspective of being diagnosed later in life (in her 70s), speaks at some length about the hierarchical nature of illness and Parkinson's place within it. 'I think it's probably, I mean obviously it's one of those problems that is almost a sort of second tier problem in comparison to cancers, for example, which everybody is aware of. But because Parkinson's is... a) it's very often older people who have it; b) it's not a terminal diagnosis; c) it's probably not as disruptive to one's life as some of the better known medical problems [...] and d) I don't think that there is a knowledge of how many people do have the problem. And I think those combined mean that there are not that many people who are interested in being made aware of what it's about.' She also points to the economic climate in which most people, if inclined to give to charity, have to make choices: 'You sort of filter them and have your chosen ones.' Very honestly, she continues: And certainly Parkinson's wasn't at the top of my radar until it was forced upon me.

Rory expresses something similar. When you don't have something 'you don't need to know a lot, right? You haven't got it. It's that simple.' For **Barbara**, there is also a stigma attached to having a 'visible but not understandable' condition: 'I think too there's a bit of a, among some people they're happier with, to consider medical problems that don't show.' In her view, cancer is less visible, 'Whereas somebody with Parkinson's who's walking along with a stick and perhaps shaking a bit, there's still a remnant I think of [...] probably the best thing to do is put people away and forget about them when they've got these things. I think there's a little bit, it's almost that people – they don't, because they don't know a lot about it, they don't know what to do, people know [...] but they don't know about Parkinson's.'

Table 20 Participants' comments on the lack of interest in Parkinson's shown by society

Second, with a simple switch of pronoun, agency changes: I have not picked Parkinson's, it has picked me. In that instant, it feels as though I have been given honorary status that helps overcome the divide between 'healthy' researcher and 'sick' participant. As I start a brief explanation of how the project has evolved, she interjects with a heart-stopping moment:

'You're enjoying it?'

Throughout the interview Sarah, like many other participants in this study, is good at anticipating and finishing off my questions, or starting a reply before I complete my thought. I am relieved that this is one such occasion, since her suggestion that I might be 'enjoying it' takes me by surprise:

J: Oh I...

S: You've met some nice people I'm sure

J: Yes

S: But people can be so nice. It doesn't cost anything to be nice, does it? (This is spoken against a scrabbling sound as she first feels for and then delves into her handbag). I'm rooting for something.

J: What are you rooting for?

S: My lip salve, I'm a bit dehydrated.

The focus switches back to Sarah, and any discomfort I feel at the suggestion I may be 'enjoying' my research fades as she moves on to issues associated with dehydration. These frequent switches in topic during the interview, combined with the rapid fire, breathy delivery of her words, demand particular focus and concentration on my part. It is only once the interview is over that its sheer emotional intensity hits me. As I sit quietly in my car before driving home I write down a few reflections, touching briefly on why I feel such unease at Sarah using the word 'enjoy' with regard to my research. Has my enthusiasm for my research been misconstrued as enjoyment?

If so, this seems unfortunate, since within two minutes of starting the interview she clearly states her antipathy towards Parkinson's: it inhabits her head, her brain, and now badly affects her body. By contrast, it inhabits only my thesis, not my body. Arguably, Parkinson's has taken up temporary residence in my mind as I have

immersed myself first in the research, and now the writing, of this study. I have certainly been gripped by participants' stories and energised by the task of giving them voice. But I have done this out of a deep interest rather than enjoyment. Nevertheless, the reality is that I do not have to live with the physical and emotional consequences wrought upon my participants by Parkinson's. I can walk away from it.

I cannot, however, walk away from Sarah's story. It is one which is hard to hear, both at an emotional as well as physical level, but it is precisely because is so hard to hear that it needs to be told. From the outset, Sarah lays bare a story that speaks predominantly to Frank's chaos narrative, the plot of which 'imagines life never getting better'(Frank 1995, p.97). Despite the parallel she draws of Parkinson's 'picking' us both, it is Sarah who has been 'sucked into the undertow of illness' (ibid, p.115). I am on the outside, looking in, aware of Frank's observation that 'all of us on the outside of some chaos want assurances that if we fell in, *we* could get out' (ibid. p.102). Sarah's narrative gives no such assurance. For much of the interview she speaks of – and embodies – a chaos narrative⁵ which 'is beyond such bargaining: there is no way out' (ibid).

Sarah is full of nervous energy, and the first few pages of the interview transcript are peppered with hasty interjections – *'I'm nervous'* *'Am I gabbling?'* *'Sorry, gabble, gabble'* *'I'm waffling on here, emotion'* – followed by an intake of breath before continuing with her next thought. As she describes the symptoms she experienced prior to diagnosis, her repetition of *'and...and...and'* demonstrates the syntactic structure so often found in chaos narratives, where 'a staccato pacing of words pecks away at the reader' rather as life 'pecks away' at the narrator (Frank 1995, p.99).⁶ Thus, from having poor balance and 'twitching' feet, the symptoms become worse:

'And I, I found myself, I didn't know that I wasn't handling my purse very well, money, dropping things and my face would go rigid and my eyes were wide and I'd look like a clown. They call it masking, don't they?'

6.6.2 'What happens now?'

It is through the reactions of others that she is made aware of what she now knows to have been symptoms of Parkinson's. At the time, however, she is simply aware of a

stiffness throughout her body. Her words ably evoke the sense of oppression, frustration and anxiety induced by this inexplicable feeling:

‘...I was just aware of the stiffness in my body and I thought, what’s the matter with me, someone give me something, give me something to take, to get this away. It was horrible, like **chains** bearing down on me, keeping my feet to the floor, and I would start walking and stop... and I couldn’t go through doorways...’

Diagnosis is a terrible shock:

‘So I was mortified, ‘Am I going to die, what happens now?’ And he said, ‘*Well it just progressively gets worse and in the end...*’ He didn’t actually say it would get you, but that’s what he meant, because in the end it **will** get me won’t it... in the end?’

This contemplation of her end, within minutes of the interview beginning, brings home the enormity of the existential challenge facing Sarah. As Havi Carel surmises, ‘we are not meant to be able to see into our future’ but rather we should be ‘propelled into our future, thrown into our projects with no premonition, no peeking.’ In this brief account of her diagnosis, in which she dares to tell me what her doctor declines to vocalise, Sarah draws me into joint contemplation of a future that ‘contrary to the laws of nature and of human nature... has exposed itself to her.’⁷

Parkinson’s may be her medical diagnosis, but ‘diagnoses mean much more to patients than simply the identification of a particular disease state’ (Toombs 1995a). The significance of her question ‘*What happens now?*’ becomes all too clear as a litany of losses unfolds. Parkinson’s robs her of her marriage, her job and, ultimately, her independence. She outlines how her husband ‘*couldn’t cope with it. He just couldn’t cope.*’ This is made all the harder to bear by her reflection that ‘*I would have done it for him, I know I would.*’ She has lost the job that she loved because ‘*my writing’s gone, I can’t write at all. It’s completely robbed me of my writing, took my job away.*’ She now lives in sheltered accommodation, because ‘*my drugs were so bad I was falling over all the time.*’

Sarah's story uncomfortably echoes Frank's supposition that 'the chaos story presupposes *lack* of control, and the ill person's loss of control is complemented by medicine's inability to control the disease' (Frank 1995, p.100). From the moment Sarah is diagnosed, her agency is diminished, starting with no control over the name of the disease now ascribed to her. As already discussed, she hates the name Parkinson's ('*a horrible word*') and its association with 'the shaking palsy.' She hates the drugs and yet is unable to function without them.

6.6.3 'Drugs as Trickster'

Indeed, drugs are the 'trickster'⁸ of the piece, enabling yet disabling; establishing order whilst creating chaos. During the interview, I pause the tape while she searches for her blister pack ('*I have to go on a blister pack now because it's just so many*') amongst a big pile of papers. She has, over the years, been through '*heaps*' of different drugs, which are only good as long as her body is able to tolerate them. On the one hand she falls less frequently than she did, '*I don't know why that is. Much better drugs I suppose.*' On the other hand:

'All the drugs have their side effects (including the dyskinesia from which she suffers throughout the interview) and there's nothing straightforward about it. The drugs can make me very uncomfortable. I hate the drugs. They have sent me into hospital with delusions and things. It's not me, it's the drugs.'

I hear the sadness and frustration in her voice and know that 'what can be told only begins to suggest all that is wrong' (ibid. p.99). The challenge for me, as the researcher and interviewer hearing this chaos narrative, is 'not to steer the storyteller away from her feelings' (ibid. p.101) and I am relieved to hear that I do not attempt this. My simple response of 'Oh dear' is barely audible as she continues with

'I hate it all. I hate it, I hate this disease.'

Listening again to this part of Sarah's story I am reminded of 'Bill' who, in Gareth Williams' research involving people with rheumatoid arthritis (RA), questions '*how the hell have I come to be like this?... because it isn't me.*' To Williams, these words indicate how 'a chronic illness such as RA may assault an individual's sense of identity' (Williams 1984, p.175). For Sarah, it is not only the effects of a chronic illness with which she has to contend, but also the effects of the drugs. In a cruel

twist of fate, the very drugs prescribed to control and manage the symptoms of Parkinson's turn rogue, aiding and abetting the disease in what – for Sarah – becomes a double assault on her sense of identity.

6.6.4 'I have Parkinson's disease – I'm not a freak'

Throughout this analysis I am struck by how difficult it is to piece together the narrative threads of Sarah's story. The interview lacks 'coherent sequence,' jumping from one thought to the next as though mirroring the incoherent nature of her condition. It is a condition of extremes:

'When I'm good, I can do anything – I can move wardrobes and beds and things. I can do anything. I'm quite strong [...] when I'm not, I can't do anything. I can't do a thing.'

It is also a condition that, for Sarah, has resulted in alienation. Her relational world has been dramatically altered by the diagnosis of Parkinson's and, as already mentioned, her sense of loneliness is intense. This loneliness is further compounded by a sense of stigmatisation that manifests itself both at a societal and personal level. She tells me, for example, how her first disabled badge had '*In-valid*' on it, '*invalid – I was in-valid, and that's how I felt.*' At a personal level, she reclaims herself, saying '*I don't care what people think any more*' at the same time outlining how in the past she has asked people not to stare at her, '*I have Parkinson's disease, I'm not a freak*'. That she does care what people think becomes apparent as she relates her experience of a couple of hours before the interview. She explains:

S: And speech is the worst thing. I have days where people just cannot understand what I'm saying, and it's so low they can't hear me and it's so garbled, it's so frustrating, I could cry every time.

J: You're speaking very clearly today.

S: I am, but when I went to the station earlier, they couldn't hear me or understand me. So I said I'd come back later. I had to get out of there. I was embarrassed. Sometimes I pretend to be deaf because it's more acceptable. Isn't that ridiculous?

J: Is that how you feel?

S: Yes. I do sign language, I learned to do sign language at night school, very early on in my Parkinson's career, shall we say.

J: Yes.

S: So I use that sometimes. I get more understanding, more response. And people don't go, '*What, pardon?*' I could punch them on the nose. I will say I'm deaf. And then they speak to ... and help me, but if I don't say that they don't help me. It's horrible.

Underlying Sarah's narrative is the 'gnawing awareness'⁹ of a lack of agency brought about by Parkinson's as she is 'buffeted by forces [she] cannot control,' trapped in a plot that 'leads to no resolution' (Frank 2012, p.47). The story that Sarah tells me is the story that she is living; not the story that she would like to be living. As she names and shames Parkinson's, she enables me to understand how 'the experience of illness is always the experience of both "having" and "being had"' (Toombs 1995). Sarah 'has' an illness, but it also 'has' her for the rest of her life:

'Parkinson's is a hell of a disease [...] I could go for 5 years or 25 years and it will still be with me. It dies when I die [...] there's no choice in the matter.'

6.6.5 'There's nothing I can do about it, is there?'

Of course, 'few individual stories have only one skeleton,' (Frank 1998, p.206) and Sarah's is no exception. Throughout the interview I sense a tension between her needing me to recognise 'the utter chaos of her life' whilst at the same time needing me to know that she is not wholly bereft of any 'resilience of the human spirit' (Frank 1995, p.101). Thus, having told me how much she hates the disease, she undercuts her own story with '*but I don't get miserable*' before immediately correcting this to

'I **try** not to get miserable about it because there's nothing I can do about it, is there?'

Something she *can* do is take solace in writing poetry and it is through this medium that she appears to reimagine and reconstitute herself. In the interview, there is a flurry of activity as she searches amongst piles of papers for a particular poem from her 'Parky' stuff. The voice recorder falls on the floor and there is a moment where I need to check that it is still working. But then calm descends on the room and, at Sarah's request, I read the poem out loud:

6.6.6 'The Pest'

You stole into my body,
You sowed your damaging seeds deep within me and you lurked there
Until the time was right.
Time matured and you slunk silently forward, oh just a bit.
Didn't want to frighten me too quickly.
Perish the thought; it would be more fun to watch me struggle.

(S: Nasty disease)

Struggle I did.
I'm a beached whale, cannot move in the bed without huffing, puffing,
And yes it drags me down to crying level.
Not for long though, for I am stronger than you.
I will beat you in the end.

My hands, my useless hands, couldn't write, draw or play my beloved piano now.
I cannot always talk but hey, I can sing, sing, sing (*S: Yes, I can*)
You can't take that away from me.
I will not home in on you and make me your slave.
No, I am out to get you, to rid my body of your all, your tendrils, your poison.

And I will...

As she reflects on this poem that envisions a future in which she 'beats' her disease, Sarah slows down for the first time in the interview. I ask her 'How does that make you feel when you hear it again?' It is an emotional moment.

'It makes me feel...'

She hesitates and then reneges on this vision of her future:

'It makes me feel, well, disturbed really, upset, because that's how it is. I won't win, but day by day I'm winning, but in the end he'll win.'

6.6.7 'Why can't I just pick up my bag and run?'

It is with a sense of unease that I am reminded of S Kay Toombs' reflection on how 'future-oriented' western culture is, demanding that 'we act now in light of projected goals and plans [and] work toward achieving future aims, future rewards' (p.101).

As I sit with Sarah, who is only three years older than me, is this not precisely what I am enacting? I am interviewing her as part of my research in order to write my thesis with a view to gaining my doctorate. As long as I remain healthy, I can afford to have dreams and make plans in order to fulfil them. For Sarah, things are so different. Her references to the future are mainly related to the unrelenting

trajectory of Parkinson's, the disease that will 'win' in the end, only dying when she dies.

If she dares to voice an aspiration, almost immediately she interrupts herself with rhetorical questions that then hang uncertainly in the air, emphasising the precarious nature of her future. She hopes to write more poetry, more stories, but having lost the mechanical ability to write she now finds that even her ability to type is waning, *'What am I going to do when that's gone?'* She would love to be able to travel, but unlike 'the healthy' she cannot simply 'routinely overlook' her body, but rather must plan for its 'insistent presence' (Toombs 1995):

'I'm very vulnerable to being pushed over because I'm wobbly [...] I have to think, every time I have to think, do I need food? How long am I going to be? Do I need lunch? Do I need this? Do I need that? And I have to think it out and it's really annoying.'

In what feels like open defiance of her illness and the future she has been denied, she asks:

'Why can't I just pick up my bag and run?'

In a moving part of the interview she tells me she would like to marry again, or at least have a 'companion' with whom she can share her life.¹⁰ Immediately, she derides the possibility:

'Who would want **this**? Who would want to be living with **this**?'

Such self-objectification suggests just how negative can be the cultural and social experience of illness, resulting in bodily alienation and highlighting how 'the rules change when you are ill [and] you become an outsider to the world of the healthy, an offensive reminder of the ugly underbelly of life' (Carel, 2007).

6.6.8 'I don't want to hear it because it's not going to happen'

Part of the offence is the existence of an illness that cannot be cured despite advances in medicine. Not only does the lack of a cure reveal the vulnerability of Sarah as the sufferer, it also provokes anxiety in those involved in her care, for it is in her story that 'the modernist bulwark of remedy, progress, and professionalism

cracks to reveal vulnerability, futility and impotence' (Frank 1995, p.97). Despite others drawing her attention to any news of medical breakthroughs, Sarah is clear in her rejection of 'the narrative force of restitution' (Nettleton 2006, p.1173).

'I can't be bothered, nothing is happening, so what's the point of reading about it? There's like a flash on the news, 'Pill for Alzheimer's in three years.' And I just ... 'Sarah, channel five, quick,' or whatever. And like I say, okay, okay, but I don't bother; I don't want to hear it because it's not going to happen. I just don't think it will happen in my lifetime. So there's no point in getting excited.'

As with so many other participants, she frames her views about medical research in terms of a cure. For a moment, she allows herself to contemplate a cure, in the same breath dismissing it. She sounds weary. Echoing Caitlin's views about the limitations of a cure, she says:

'And even if they found a cure today, how far down the queue would I be? Would I be, because I've had it longer? Or because I'm younger? I had it younger, where would I sit in the queue to get it? Would it take three years before I could get it? How much worse would I be in three years' for waiting? You know what I'm trying to say?'

Sarah's is so caught up in the day-to-day immediacy of her condition that there is little space into which a future can breathe. I am left with a sense that for Sarah the future, rather than opening out, is closing in on her. Reflecting on her story in the context of other participants' accounts, I am aware that she would derive little comfort from Julian's view that '*there's progress all the time, so, who knows, who knows what the future holds. It's umm, as I've said before – there's never been a better time to have Parkinson's.*'¹¹ Similarly, I am aware that for other participants, Sarah's story – and her embodiment of Parkinson's – may provoke considerable discomfort. After all, her present, with its dyskinesia, freezing and occasional incontinence, is the possible future of which they speak in fearful tones:

As **Rory** told me: ‘The other person I’ve met is someone who’s had Parkinson’s, my age, he’s had it for twenty something years and he was frightening. He’s got severe dyskinesia and terrible movement problems.’

Kay, too, having met people much more severely affected than herself is fearful: ‘that could be me in ten years, who knows?’ further speculating that ‘when I start to sort of have dyskinesia, if, or when I start shuffling, probably, at the moment I’m thinking I won’t go anywhere, won’t go out. I would hate to be looked at.’

Pat: ‘Then I made the mistake of going to the support group at...And that is really - I think that they’re lovely people but it is so depressing... There were quite a few ladies in wheelchairs with their necks strapped up because they couldn’t keep their heads still and all that sort of thing. It was very sort of – and I just looked at them....’

Ted, who in his professional life has worked with people with Parkinson’s, does not want reminders of his future: ‘I’ve got to try to do the best I can. But, especially when I’m on my own, I do get depressed because... think what the consequences are going to be in the future. The knowledge, it’s got to do with the knowledge I’ve got. You end up in a wheelchair, you know, unable to control your bowels or whatever.’

Table 21 Fear of the future

6.6.9 Post script: ‘It’s interesting listening to you’

Although Sarah’s story may be uncomfortable to hear, Frank is quite clear that ‘to deny a chaos story is to deny the person telling this story and people who are being denied cannot be cared for’ (p.109). Perhaps it is serendipity that one of her carers, Jean, comes to make her lunch and, at Sarah’s invitation, takes part in the latter part of the interview. For Jean it is *‘interest[ing] listening to you’* and she is encouraging of Sarah speaking out when she mentions that some of her carers do not know how to handle Parkinson’s: *‘You need to say that. You need to say that.... I think you ought to say it to people, the people that are caring for you.’* In Jean’s presence Sarah describes herself as a ‘sufferer’ - although she wants us to know that she does not perceive herself as a ‘martyr’ - and although the act of telling her story may not have ‘liberated’ her from the story she no longer wants to tell, I leave the interview hopeful that the dialogue that has taken place may open up the act of spreading ‘the concentric circles of witnessing suffering’(Frank 2013, p.195).

¹ According to the PUK website, the aim of the post cards was to help raise funds for research by helping “raise awareness of just how urgent it is to find a cure” - See more at: <http://www.parkinsons.org.uk/news/16-april-2012/major-research-announcement-launches-parkinsons-awareness-week-2012#sthash.Ujllnuh1.dpuf>

² As outlined in the Hoehn and Yahr table (p.135) describing disease progression, symptoms do usually present unilaterally in the early stages. Later in the interview (p.10) Rory acknowledges this, saying ‘*So I thought it was symmetric for some reason. I can’t work out why.*’

³ Hawkins, Anne “Two Pathologies: A Study in Illness and Literature.” *The Journal of Medicine and Philosophy*, 9:3 (August 1984), 231-252. Cited in Register, C. (1987). *Living with Chronic Illness: Days of Patience and Passion*. New York, Macmillan.

⁴ As already outlined, Keith is in a paradoxical situation whereby he recognises that without advances in medical technology (DBS) he would be a ‘vegetable’ and yet it is medical technology that may lead to ‘loss of control’ if it is used to keep a ‘body functioning long after [one’s] integrity as a person has been destroyed.’ (Toombs, 1995)

⁵ Frank explains that such stories cannot literally be told but can only be lived – ‘to turn the chaos into a verbal story is to have some reflective grasp of it.’ I would argue that Sarah does both within her interview. She turns events from the past – in which the voice of chaos can be identified – into a verbal story, whilst at the same time manifestly living a chaos story where ‘the body is imprisoned in the frustrated needs of the moment’ (1995, p.98)

⁶ This is my rendering of Frank’s analysis of an excerpt from Charmaz, K. (1991). *Good Days, Bad Days: The Self in Chronic Illness and Time*. Berkeley, University of California Press.

⁷ Havi Carel is a philosopher who, in her work, frequently reflects on mortality. She was diagnosed with a very rare, terminal illness in 2007 and given 10 years to live. Quotes cited here are taken from Havi Carel: My 10-year death sentence. <http://www.independent.co.uk/news/people/profiles/havi-carel-my-10year-death-sentence-440805.html>

⁸ Frank writes about the ‘trickster’ as a ‘character’ in a story. The drugs in Parkinson’s so affect people that, for me, they take on an almost human form. Maybe, though, the tricksters are Medical Professionals? I could not help but substitute the word ‘drug’ each time ‘gift’ appears in the following sentence: ‘Tricksters often bring a *gift* that is crucial to the possibility of people becoming fully human, but the *gift* is shaded – tricksters also make life dangerous for humans (2010, p.45).

⁹ This metaphor is borrowed from Arthur Frank: ‘Humans know, abstractly, that every heartbeat is a hope for the next one. Illness transforms that abstract knowledge into a constant, *gnawing awareness*. Frank, A. W. (2009). “Tricksters and Truth Tellers: Narrating Illness in an Age of Authenticity and Appropriation.” *Literature and Medicine* 28(2): 185-199.

¹⁰ Sarah’s words bring to life S Kay Toombs opinion that ‘what patients need most is someone to accompany, to be with them on the life journey that is their illness.’ Furthermore, Toombs suggests that ‘this is especially true as they come to grips with the reality that cure is not a possibility.’

¹¹ Julian’s words unnervingly echo Margaret Bourke -White who, after pioneering brain surgery, wrote: ‘I am born in the right century, in the right decade, and even in the right group of months to profit from the swift running advance of modern medical science’ (p.380) Bourke-White, M. (1963). *Portrait of Myself*. New York, Simon and Schuster. Sadly, her optimism was premature and, despite a second operation in 1961, she deteriorated until her death in 1971, by which time chemothalamectomy had been abandoned. Chemothalamectomy involved drilling a hole in a patient’s skull and injecting alcohol onto a portion of the brain known as the thalamus (Barron H. Lerner). <http://www.theatlantic.com/health/archive/2013/09/the-first-female-celebrity-to-embrace-parkinsons/279189/>

CHAPTER 7: CLOSING THOUGHTS

The central aim of this study has been to gain insight into the lived experience of people faced with Parkinson's, a serious, neurological disease. In the initial stages of designing the study, the focus was clearly on participants and what they said and my role appeared to be that of little more than a record keeper. However, having been introduced to the work of Arthur Frank and Laurel Richardson, I began to dare to think that dialogical narrative analysis (DNA), with its emphasis on understanding how people's lives are affected by stories, might be an approach with which I could experiment. The more I read about it, the more this 'practice of criticism' (Frank 2010, p.73) spoke to me. At the same time, to attempt DNA felt a huge responsibility, not least because I would have to acknowledge openly and visibly my own role in shaping the manner in which participants narrated their stories. I would not be the anonymous researcher writing up my findings. Rather, I would need to be in the thesis with my participants, and I would need to trust that the process of writing would be 'the discovery' and the writing itself the 'finding.'^a

Taking these decisions resulted in the spirit of the thesis changing. I became driven by the desire to capture and reproduce participants' stories in a way that retained the distinctiveness of their voices. At the same time, I was encouraged by the view that 'every narrative analysis needs to discover its own singular way to proceed' (2010, p.112) and adopted different ways of using DNA for each of my data chapters, whilst nevertheless trying to remain true to the five methodological commitments outlined by Frank (see Methodology chapter, p.80). As a consequence, in drawing this work to its close, I am mindful of his caution neither to 'finalise' participants as storytellers, nor to 'summarise findings' which might be seen as 'ending the conversation' and taking a position apart from and above it (2012, p.37). Instead of 'findings' I therefore offer some reflections on whether this thesis has, indeed, contributed to the gaps I identified in the literature. I shall also reflect on some of the challenges experienced in undertaking the work and conclude with the implications for research and clinical practice in the future.

^a Arthur Frank on 'Writing as a Form of Analysis'
<https://www.dur.ac.uk/writingacrossboundaries/writingonwriting/arthurwfrank/>

7.1 Contribution to the literature

First, I wish to reiterate my view that any methodological standpoint can only be partial, and therefore any contribution this thesis makes to the literature is part of an ‘ongoing process of reassembling what will never be a whole story’ (Frank 2010, p.103). However, by adopting an approach that has not hitherto been used within the research on Parkinson’s I have endeavoured to build on previous studies while at the same time bringing a fresh perspective to the way in which people’s experiences of Parkinson’s are heard.

Asking people to discuss their illness experience without any pre-defined agenda brought forward considerable ‘inside knowledge’ (Nijhof, 1996) which called out as needing to be written about. In particular, participants’ detailed accounts of the diagnostic process have provided me with the empirical material for participating in the ‘reassembling’ of a part of the Parkinson’s story that is largely absent in the literature: the moment of diagnosis. Similarly, participants’ narratives afford a significant contribution to the debate on non-motor symptoms, identified by neurologists themselves as an area of ‘unmet need’ requiring ‘more research to recognise and manage [them] effectively in clinical practice’ (Todorova et al. 2014, p.320). The importance of non-motor symptoms has frequently been highlighted in the qualitative literature relating to Parkinson’s, but rarely through narrative representations. I hope that, in particular, Rory, Keith and Sarah’s narratives, might help broaden any understanding of the importance of non-motor symptoms by allowing us to hear the different ways in which their experiences of non-motor symptoms both shape, and are shaped by, their stories. Finally, by placing participants’ voices in dialogue with the external disease narrative and differing representations of Parkinson’s I believe this study adds to the literature by showing the importance of stories in reclaiming an understanding of the lived experience of Parkinson’s from others’ narrative representations of them (Frank 2009).

7.2 Challenges

One of the biggest challenges arising from my decision to use DNA as a means of exploring participants’ stories was facing the reality that, ‘from the original collection of stories, comparatively few will actually be discussed in the research report’ (Frank 2012 p.43). Participants were so generous with both their time and their stories that I wanted to reciprocate by ensuring that each of their voices was

heard. However, as I experimented with the analytic process I realised that, in order to remain true to the principles of DNA, I would have to accept that I could not place all of my participants' voices in the foreground. At the same time, accepting that some participants' voices would play more of a background role was helped by remembering participants' motivation for participating in this study: a strong desire that my research should contribute to an understanding of what it is like to live with Parkinson's. As the thesis took shape, I became increasingly certain that DNA allowed me the means by which I might best capture 'what it's like to be sitting at this side of the table' (Bill) and this helped overcome my anxiety at not presenting each and every story.

Although DNA enabled me to work with stories in a way that retained their vividness and authenticity, I am also aware that the completeness of the pictures drawn in the final chapter might be seen to pose a challenge to typical thinking with regard to the confidentiality and anonymity for research participants. Whilst I have worked hard to ensure that the risk of participants being identified by anyone but themselves remains small, I cannot avoid the admission that self-recognition might happen in a few cases. I did not undertake to share my transcripts with my participants and neither have I shared the stories herein. However, when I move on to place these stories more firmly in the public domain I shall make decisions about who to include, remaining mindful of my ethical responsibilities to each individual participant. It might be the case that the voices that 'called out' within my thesis will not be those I choose to expose to the public gaze.

7.3 Implications for future research and clinical practice

My decision to use DNA as a means of working with my transcripts means that there are aspects of people's stories that deserve further exploration as well as many stories that remain untold. My use of appendices in this thesis has been, in part, an attempt to reflect the richness of 'background' participants' accounts whilst at the same time acknowledging the parameters inherent in undertaking research. I certainly intend to contribute further to the qualitative literature through publishing articles based on important themes emerging from within and across participants' narratives. These include 'breaking bad news,' non-motor symptoms, and participants' reactions to living with an incurable, degenerative illness in a society intent on finding a cure. In addition, through meeting so many people with

Parkinson's I have become very aware of the vital role played by carers. Many participants spoke to me about the need for research that gives voice to the carer experience and this appears to be an area that, having been acknowledged and explored in relation to conditions such as dementia, is in need of further study in relation to Parkinson's.

However, before drawing this thesis to a close, it is important briefly to highlight some of the possible implications for clinical practice that have arisen as a consequence of listening carefully to participants' stories. This is not an attempt to 'summarise findings' but rather a desire to acknowledge the potential for DNA to increase the audibility of certain stories and recast how they might be understood in the clinic (Frank, op.cit, p.50). In particular, there is scope for acknowledging and addressing the need for further training of clinicians in the art of breaking bad news in the context of a Parkinson's diagnosis. As discussed earlier, participants' stories revealed considerable shortcomings in the manner in which the diagnosis encounter was handled, not least the degree to which, in many instances, it was treated as a matter of routine and passed over as a 'non-event' by some diagnosing clinicians. It therefore feels important that the latter are not left alone in undertaking this difficult job, but rather offered the benefit of an environment in which they might, like Kay's neurologist, feel able to ask *'How could I have done it differently?'* The stories detailed in this thesis not only offer the opportunity for clinicians to hear patient views as told to somebody not involved in their medical care, but also provide empirical material for usefully informing training and discussion aimed at sharing good practice.

Participants' narrative accounts also draw attention to the need for reliable information and timely support following the diagnostic encounter. Despite - or maybe because of - the plethora of material about Parkinson's now available over the internet there appears to be room for the development of better 'staged' information given to people both at diagnosis as well as any follow up appointments. In addition, participants' stories reflect the inconsistencies of support available to them through the national health system. Whilst this is not surprising, given that not all health authorities have Parkinson's specialist nurses in place, the many voices in this thesis clearly underscore the efficacy of timely access to a nurse specialist and

the desire for an expansion in the number of Parkinson's specialist nurses with a manageable caseload.

7.4 And finally...

Letting go of this thesis is perhaps the hardest aspect of the whole process. It is through the generosity of my participants that I have been able to develop both my research skills and the confidence to present their stories in the way that felt most true to their experience. I have lived and breathed their stories for more than three years. In that time I am very aware that their lives have continued. I am also aware that the progressive, degenerative nature of Parkinson's means that they will have revised - and will continue to revise - the stories they tell of their changing illness.

Just as the ability to revise and tell stories depends on the narrative resources available to them, so too the breadth of available narrative resources depends on stories being told. But it is only once the story is told that it can become 'a narrative resource available to others who seek, and often struggle, to express their experiences' (Frank 2009, p.190). The story of my thesis is now told. Practically, there must be a last word. However, I hope the stories that have shaped my thesis might expand the narrative resources available on Parkinson's and 'continue to release their energy' as fuel for a continuing dialogue (Frank 2013, p.221).

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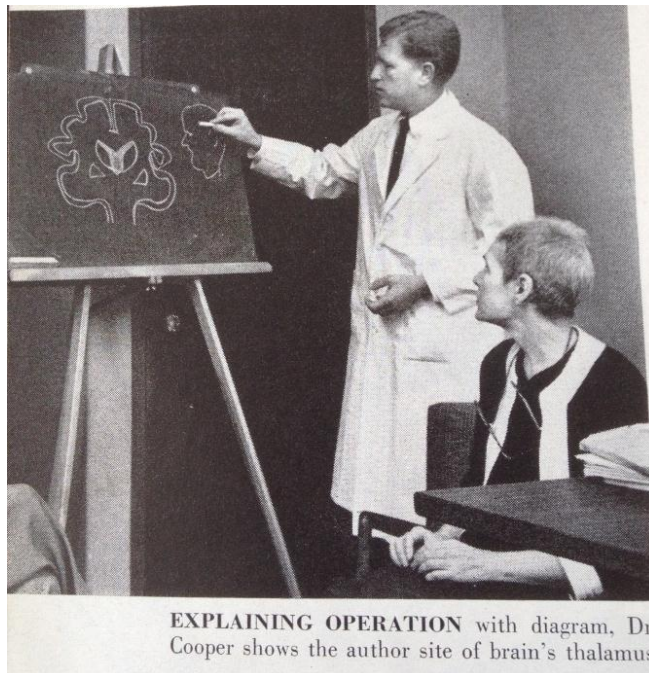
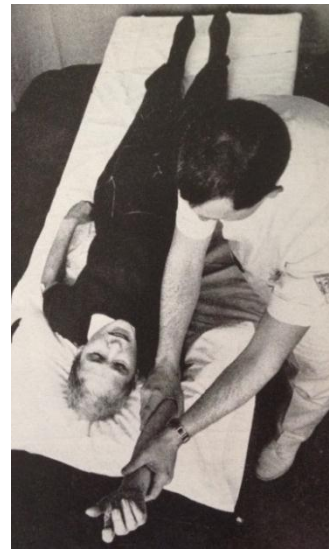
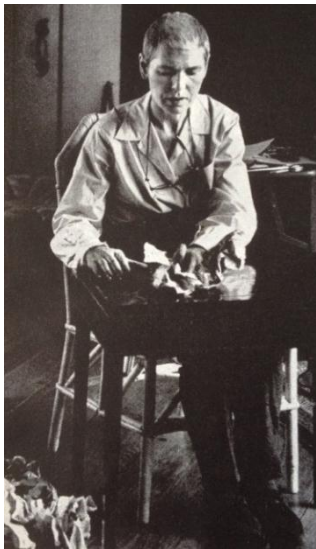
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Appendix 1: 'Stories are [...] told to be echoed in future stories'



A Brave Woman's Own Story: Famous Lady's Indomitable Fight – Life Magazine, June 22 1959



Appendix 2: PUK Advertisement

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

Hello research supporter,

The **Brighton and Sussex Medical School, University of Sussex** has a new research participation opportunity.

Researchers at the **Brighton and Sussex Medical School** are looking for **30 people with Parkinson's** to take part in a study investigating what people with Parkinson's think about medical research.

You may be eligible to take part if you have been **diagnosed with Parkinson's** and **live in Brighton, Hove, East or West Sussex, Surrey and Kent.**

About the study

The researchers are carrying out a study to find out what people with Parkinson's think about medical research. They are interested in how people discuss research and how they see it fitting into their lives after being diagnosed with Parkinson's.

The research is part of a larger project looking at the social impact of recent developments in stem cell research and neuroscience. This study will make sure the voice of people with Parkinson's is integrated into the larger project.

The researchers need to carry out a one-off interview with **30 people with Parkinson's** that will last around one and a half hours. Participants would choose where to meet the researcher. For example, in your home or at a mutually agreed location.

After the study is completed, the researcher will send you a short report of the main research findings.

More information is in the participant information sheet and flyer which are attached to this message.

The study is funded by the Wellcome Trust.

Who manages this opportunity?

Researchers at the **Brighton and Sussex Medical School** are responsible for this participation opportunity. **This opportunity is not managed by Parkinson's UK.**

It is your choice to take part in the activity and Parkinson's UK cannot take responsibility for it. If you are interested in participating, you should contact the researcher directly for more information and talk to your own doctor, healthcare professional or other advisors before making any decisions.

Interested in participating?

This study is looking for **30 people** who have been **diagnosed with Parkinson's**, and **live in Brighton, Hove, East or West Sussex, Surrey and Kent**.

The closing date for recruiting participants for this study is **30 September 2012**.

What to do next

Please circulate this participation opportunity to members of your Parkinson's UK local group, Parkinson's nurse, family and friends.

If you are interested in taking part, or wish to find out more information or whether you are eligible for the study, please contact the researchers directly:

Jane Peek, PhD Student Researcher

Brighton and Sussex Medical School, University of Sussex

Tel: 07557 376 626

Email: j.peek@bsms.ac.uk

Appendix 3: Participant Information Sheet



Participants' views on medical research in the context of Parkinson's disease

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully.

Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

I am conducting this study as part of my Wellcome Trust funded PhD. It is part of a larger project within the London & Brighton Translational Ethics Centre (LABTEC). Its aim is to investigate the social impact of recent developments in stem cell research and neuroscience, and the interaction between scientific research and clinical treatment. As part of this project, we are looking at the experiences of people diagnosed with Parkinson's disease.

In order to ensure that the patient voice is heard, I wish to understand your experience of Parkinson's disease. In the context of a broader discussion about your life since diagnosis, I would like to discuss your attitudes towards medical research. However, I am keen not to restrict our conversation in any way and my project is designed more generally to give voice to the experience of people with Parkinson's disease, in the awareness that not everyone will be interested in the topic of medical research.

2. Why have I been chosen?

You have been chosen because you have been diagnosed with Parkinson's disease.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason.

4. What do I have to do if I take part?

I shall visit you at a place of your choosing to conduct an interview. This may be in your home, if that is convenient, or at another mutually agreed location. If the

latter entails travel for you, you will be reimbursed reasonable travel expenses. The interview will be for as long as you feel willing/able to talk (usually somewhere between an hour and an hour and a half). If, at the end of the session you feel that there is more that you would like to say, it should be possible to meet again. With your consent, the interview will be recorded and transcribed.

5. What are any possible disadvantages and risks of taking part?

It will take time out of your day, but every effort will be made to minimise inconvenience and to ensure your comfort in the interview process. Whilst many people value the opportunity to talk about their experiences, it can be tiring. If you wish, it will be possible to take a break or stop at any point during the interview.

If, at the end of the interview, it has brought up issues you wish to discuss further, we shall be able to refer you to more expert sources of support.

6. What are the possible benefits of taking part?

Although this research is unlikely to be of direct benefit to you, it will give you the opportunity to talk about your experiences and express your opinion on a variety of subjects to an interested, non-judgemental listener who is not involved in your medical care.

7. What will happen if I don't want to carry on with the study?

If you agree to be interviewed, you can withdraw at any time during or after the interview. However, we would ask to be able to use all data collected up to the point of your withdrawal.

8. Complaints

We do not anticipate any problems arising during this study. If you do have a concern, however, about any aspect of this study or the conduct of the researcher, please feel free to contact my research supervisor Professor Bobbie Farsides (contact details below).

9. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Every step will also be taken to assure your anonymity. However, in reporting the data we would like permission to refer to your age and gender.

10. What will happen to the data?

The data recorded from the interview will be analysed for a final written project.

11. What will happen to the results of the research study?

The results of the research study will be written up and form the basis of my PhD thesis. Parts of the study may also be submitted for publication. An additional short report of the research findings will be provided for distribution to participants.

12. Who is organising and funding the research?

The research is a PhD project funded by the Wellcome Trust as part of a Research Grant awarded to the Brighton and Sussex Medical School.

13. Who has reviewed the study?

The project has been academically reviewed on behalf of the Wellcome Trust (the funders of this project). It has also been reviewed and approved by the Brighton and Sussex Medical School (BSMS) Research Governance and Ethics Committee (RGEC). In addition, it has approval from the National Research Ethics Committee (NRES – South East Coast).

Thank you for taking the time to read this information sheet.

Contact Details:

Jane Peek

PhD Student Researcher

Brighton & Sussex Medical School

University of Sussex

Brighton

BN1 9PX

Tel: .07557 376 626

Email:j.peek@bsms.ac.uk

Professor Bobbie Farsides

Professor of Clinical and Biomedical Ethics

Director of Student Support

Room 3.04 BSMS Teaching Building

Brighton and Sussex Medical School

University of Sussex

Brighton

BN1 9PX

Tel 01273 877889 (PA)

Email b.farsides@bsms.ac.uk

Appendix 4: Flyer



Views on medical research in the context of Parkinson's Disease

THE STUDY

My name is Jane Peek and I am a mature student studying for a PhD at Brighton and Sussex Medical School. I have returned to full time study after many years working in the voluntary sector. I am conducting a study into what people with Parkinson's disease think about medical research, and how they discuss it. My work is part of a larger project, funded by the Wellcome Trust, looking at the social impact of recent developments in stem cell research and neuroscience.

I am aware not everyone will be interested in the topic of medical research, but my project is designed to give voice to the experience of people diagnosed with Parkinson's disease, so do please consider participating even if you have no direct interest in, or involvement with, medical research.

THE INTERVIEW

I am seeking to interview people individually, for up to an hour. If you are willing to participate, I would ask your permission to record the interview in order that I may concentrate fully on what you are telling me, rather than taking notes. It would be your choice when and where the interview takes place. I would also be happy to have a follow up meeting if you felt that it would be helpful. I would ensure your anonymity in my study, and all information you give me will be kept confidentially.

The project has been given ethical approval by

The Research Governance and Ethics Committee of Brighton and Sussex Medical School (BSMS)

And

The National Research Ethics Committee (NRES - South East Coast)

If you would like to find out more, I am at the conference today and would be happy to talk to you about it – please feel free to approach me. Alternatively I would be delighted to hear from you at a later date. Please feel free to phone or email or write to me at:

Brighton and Sussex Medical School
University of Sussex, Brighton
BN1 9PX
j.peek@bsms.ac.uk
07557 376 626

Appendix 5: Consent form

CONSENT FORM

Patients' views on experimental research in the context of Parkinson's Disease

Name of Researcher: Jane Peek

	Please tick box
I confirm that I have read and understand the information sheet dated 08.08.2011, Version 1 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	<input type="checkbox"/>
I understand that relevant sections of any data collected during the study may be quoted in the final paper and that it will be made anonymous unless I ask to be named.	<input type="checkbox"/>
I agree to take part in the above study	<input type="checkbox"/>
I agree to the interview being recorded	<input type="checkbox"/>
I am happy for my data to be retained if I withdraw from the study	YES / NO
In any publication, I would like to be fully anonymous	<input type="checkbox"/>
I would like to be quoted by name	<input type="checkbox"/>
I understand that the research data collected during the study may be looked at by individuals from the sponsor organisation and from regulatory authorities where it is relevant to my taking part in the study. I give permission for these individuals to have access to my records.	<input type="checkbox"/>

Name of Participant
(Print)

Date

Signature

Researcher
(Print)

Date

Signature

Appendix 6: Vignette - Edna

For me, Edna tells the story of a woman whose life has been greatly diminished by the acquisition of Parkinson's. Physically, she is augmented. She says she has put on weight and is unhappy about it. But her physical gain corresponds with her physical losses as well as her loss of independence and thereby loss of control. She is in a wheelchair; her speech is very difficult to understand; there is a slight smell of wee in the house; she laments the wearing of pads; her view on the world has been reduced to the plate glass windows into the garden and the importance of a bird bath and waiting for glimpses of robins, pigeons, squirrels or an occasional fox. Even the technology designed to help her have access to an outside world through radio, television and telephone is faulty, putting her out of reach. Appointments ensure some access with the outside, as well as significant dates in the calendar, like Christmas. Otherwise, she has become reliant on carers and her husband. There is an awful vulnerability.

Her appreciation of the help she receives has a very definite counterbalance. She comments on the fact that she can no longer go out in the evenings because she has to be back in time for the carers- and they don't always turn up at the appointed time, but she nevertheless has to be there. Her husband's help also comes under scrutiny. She acknowledges that he does his best, but nevertheless says that he *'gets fed up with me.'* She doesn't like respite care – *'well it's not nice really - in surroundings where other people have gone to die really.'* She seems jealous of his paying attention to the carers whereas she *'can't even speak to him'* because he hides behind his newspaper. He doesn't cook food the way she would like it, and after he has been to the shops she has to try and prise information out of him about whom he has seen or spoken to. There is a further hint of jealousy - or implicit criticism- associated with her perception of how well a friend of hers with MS is looked after by her husband:

E: 'The nicest home round here...a friend we met in Majorca, she was in there for good. She was 6 months, 8 months there or something and she couldn't speak a word to anybody...and she'd got MS...and her husband used to go there every morning, be there at half past eight, to make sure she'd had her breakfast, and he'd stay until he'd made sure she'd had her lunch...went back to Stratford...'

J: Gosh....

E: He was so dedicated...'

Her recollection of the life she has lived can only be a hint of what it must have been. Edna struggles to talk and each sentence is an effort. There is talk of cycling and dinner parties. She is proud of her previous organisational capacity, and this comes through both in the party she arranged for her husband's 70th birthday and in the job she was assigned to do at the bank once she was no longer able to work behind the counter.

So affected is she by the Parkinson's, that I find it hard to conjure up an image of how she may have been in those earlier days, and the sadness I feel is underlined by her reflections on the adjustments that have had to be made. These adjustments range from giving up bridge (couldn't turn the cards over) and cycling (turned a corner and fell off so she decided '*I can't do this anymore*') to an amazing, unprompted, portrayal of the loss of physical capacity that seems, also, to symbolise the closing in of the four walls around her.

'When I left work... obviously I was still walking...and I used to walk into X to get my shopping ...trolley...and walk home again. Then, I got to a stage where I couldn't do that... and Frank would take me in with a car.... and I'd walk back. Then I couldn't do that. And then I used to have a taxi back...then afterwards I couldn't manage.... with that, so Frank would help me shop.... mmm...that got to be too much. Now he goes shopping! Can't get me in and out of the car and shop.... goes up and down the High Street, needs to push...shop, make room for it to come home with. So it's...I do go occasionally...got some shoes...umm, because...umm...it was... stretching, shoe shops, they do a size D or something...but we brought them home and they didn't fit me around the house or anything ... went back and I've ordered some new cozifoot ones which are doubly wide or something...Oh they're here.'

The bleakness is emphasised after the interview, when her daughter and husband return. We sit and eat lunch - sandwiches - and I find it painful to watch Edna attempt to get the sandwich to her mouth and suck her drink up through a straw. It is neither elegant nor dignified. To add to the indignity, having been the focus of attention in the interview, conversation is suddenly outside her reach. She is unable to interject easily into a conversation and when she does try it is unrelated to the topic of conversation and her sentences are completed for her by her family. Initiating conversation is equally hard. As the person who has interviewed her, I recognise a degree of relief in having others around me who are easily able to initiate and respond to conversation, whilst feeling an awkwardness in observing Edna's partial and unintended exclusion.

Appendix 7: Journal entry - interviews

I still remember with a degree of surprising vividness all the interviews I have undertaken for this study. Of course I have had the transcripts - as well as the voice recordings of my participants - to remind me of the time I spent with them, and listening to recordings has enabled me to hear again the inflections in people's voices; the surges of energy and enthusiasm; the pauses for reflection; the hints of tiredness; or the occasional moments of overwhelming emotion.

For some, there are times when the voice – often a difficulty in Parkinson's^a – becomes almost inaudible or so indistinct that transcription has proved difficult. In one interview, the sound of a crumpled tissue rubbing against a trouser leg is clearly audible as the participant's tremor increases; in another, it is painful to hear again the considerable pause imposed by extreme dyskinesia, which threatened momentarily to divorce the participant from his chair. I re-experience embarrassment as I listen again to the moment I spotted my sitting room curtain material hanging in an adjacent dining room and could not help but comment on it;^b on the other hand, I cannot help but smile as I return to an office- based interview and realise that the conversation is accompanied by the sound of bubbles popping in the froth of the cappuccinos we were drinking.

Reading and re-reading transcripts and listening to the interviews have certainly played their part in keeping each interview alive. But I have become increasingly aware of the importance of visual memory, and the realisation that the body was ever present, telling its story and reinforcing the view that 'people telling illness stories do not simply describe their sick bodies; their bodies give their stories particular shape and direction' (Frank 1995, p.27). This seems particularly apt in the case of Parkinson's, where its manifestations can take a very visual form for the observer: possibly a mask-like face; a tremor; stiffness and rigidity; a shuffling gait; constantly blinking eyelids; a preciseness of movement or rolling dyskinesias being amongst the many possibilities.

These physical signs do not in themselves account wholly for my ability to recall the individual meetings. Rather, over the course of 37 interviews, sitting with many of the different ways that Parkinson's can be embodied, I became distinctly aware of my own body: its stillness (I had never thought of myself as a particularly 'still' person – I often feel cross with myself as I catch myself over- using hand gestures) or, conversely, speed of movement and ability to react when required - switching the small voice recorder on with apparent ease; making a quick note on paper with a pen; or taking a sip from a cup of coffee or glass of water as required. I also became more aware of my voice and my ability to

^a See Methodology chapter: 3.5.6

^b Conversation outlined in Methodology chapter – see section re Interviews

maintain or alter its volume at will to ensure audibility, as well as articulate each word, even when tired.

On reflection, interviewing people at all different stages of Parkinson's seems to have thrown me into recognising what Arthur Frank refers to as "other-relatedness" – a "shared corporeality [which] affects who we are" and understands that "the shared condition of being bodies becomes a basis of empathic relations among living beings" (Frank 1995, p.35).

How best to represent this in my thesis remains problematic if one subscribes to his criticism that "hearing the body in the speech it begets" cannot be done without "reducing the body to a thing that is described"(ibid. p.27). However, given the medium for this study *is* a written thesis, it is through words on paper that I shall nevertheless endeavour to convey the stories that people told me verbally, as well as the stories their bodies told me.

Appendix 8: Prevalence

‘Has nobody counted?’: The lack of knowledge about Parkinson’s reported by PUK is, of course, worrying when one considers that it is not only “one of the commonest neurological conditions,”^a but actually the “second most common neurodegenerative disease after Alzheimer’s” (de Lau and Breteler 2006, Casner 2012). Phrasing it slightly differently, PUK describes it as “the second most common chronic neurodegenerative condition in older people especially beyond the age of sixty.”^b Statistics are, however, a moot point with one of my participants, Sheila (44/53). Commenting on the number^c of people diagnosed with Parkinson’s she expresses considerable frustration:

S: I think, I think papers and journalists are terrible – because something that’s always quoted is the figure of 120,000 people.

J: Yes, I’ve come across that a lot.

S: Yeah - and I think that over all these years they’ve kept, used that same figure - first of all how can it be 120,000 people? Surely it must be 120,563 or something, so you know, the figures are just not correct one way or the other – the figures are totally wrong, umm, either then or now, that’s the figure that’s always quoted and I think to myself has nobody counted? I don’t think they have actually, I don’t think the number of people with Parkinson’s is known...And I think for heaven’s sakes, why not, you know? ... It seems fundamental. They should know. I get cross with that side of things, yes...

Sheila’s frustration is less about the number *per se*, and more about what the inaccuracy of that number represents. I sense, during her interview, that she feels a diagnosis of Parkinson’s has condemned her to living with a condition that is neglected in contrast to other diseases, such as cancer, and that failure to revise the number of people living with the condition is symptomatic of that neglect, ultimately resulting in a lack of understanding by the general public.^d

^a The National Collaborating Centre for Chronic Conditions. Parkinson’s disease: national clinical guideline for diagnosis and management in primary and secondary care. London: Royal College of Physicians, 2006.

^b According to PUK’s publication: “Parkinson’s prevalence in the United Kingdom” (2009). This can be accessed on their website http://www.parkinsons.org.uk/sites/default/files/parkinsonsprevalenceuk_0.pdf

^c Prevalence is the total number of cases in a given population at any one time vs. incidence which is the number of new cases in a specified time frame.

^d Soon after interviewing Sheila, PUK announced a revised prevalence figure of 127,000 for the number of people living with Parkinson’s in the UK, in recognition of the importance of numbers in health-care planning and service provision. The announcement was made on 23/01/2012 and can be accessed via the PUK website at: <http://www.parkinsons.org.uk/default.aspx?page=12298>. Please see [Prevalence and incidence of Parkinson’s](#) (above) for further discussion.

Prevalence and incidence of Parkinson's

Previous prevalence studies have been small and idiosyncratic, making extrapolation to the general UK population difficult - and arguably unusable - since estimates ranged between 51,000 and 120,000. As a consequence, Parkinson's UK (PUK) has calculated a new prevalence using the world's largest computerised database of anonymised longitudinal records – the General Practice Research Database (GPRD).^e The results are based on 2009 figures – the most recent year for which data was publicly available.

There are now thought to be approximately 127,000 people living with Parkinson's in the UK, of whom more are men than women (a ratio of almost 6 men for every 5 women in the U.K.), and of whom the majority (c. 100,000) are in the age range 70-85+. Certainly, both incidence^f and prevalence increase with age, but it is important to note that the figures indicate some geographical variation, with the highest prevalence rate being in England (approximately 28 people diagnosed for every 10,000 of the population) and the lowest in Scotland (approximately 24 people diagnosed for every 10,000 of the population).

Working out the incidence is an even less precise science and currently this is thought, annually in the UK, to be between 4 - 20 for every 100,000 of the population (Chaudhuri, Clough et al. 2011).

Although this study focuses on people living in England with Parkinson's, I felt it was important briefly to consider Parkinson's statistics in a global context. Thus, reports of prevalence in the U.S.A. suggest similar difficulties in establishing accurate figures, the current estimate ranging from between 750,000 – 1.5 million living with Parkinson's (Chaudhuri, Clough et al. 2011, Fritsch, Smyth et al. 2012). Again, studies suggest geographical variation, with substantially higher rates of Parkinson's occurring in the Midwest/Great Lakes region and along the northern US seaboard (Fritsch, Smyth et al. 2012). Not surprisingly, global estimates are not precise and the number of people living with Parkinson's worldwide is thought to be anywhere between 6 and 10 million people.^g

Ethnic distribution of Parkinson's is, again, not fully understood, and although there is some suggestion that it is less common in the black population, it has nevertheless been found in

^e This covers approximately 7.2% of the UK population.

^f Incidence is the number of new cases in a specified time frame.

^g Various Parkinson's websites carry statistics about prevalence and incidence. Suggested sites for information based on academic studies include : http://www.pdf.org/en/parkinson_statistics or <http://www.epda.eu.com/en/parkinsons/life-with-parkinsons/part-1/prevalence-of-parkinsons-disease/prevalence-by-country/>

all ethnic populations studied. The prevalence for each country per 100,000 of population, in those countries in which it is known, from highest to lowest is as follows:^h

Albania 800, Egypt 557, U.S.A. 329-107, Canada 317-167, Israel 256, Japan 193 - 76, San Marino 185, Faeroe Islands 206-183, Japan 192 - 76, Germany 183, Spain 170-122, Italy 168-104, Finland 166-120, Bulgaria 164-137, Estonia 152, Australia 146-104, Wales 142, England 139-121, Portugal 135, Cuba 135, Canada 125, China 119-57, Scotland 129, Norway 102, Thailand 95, Sweden 76, New Zealand 76, Nigeria 67, Poland 66, Jordan 59, Bolivia 50, Libya 31, Colombia 31, Tanzania 20, Korea 19, Ethiopia 7.

It is important to note that prevalence differs from country to country and can even differ within countries, e.g. the prevalence amongst Bulgarian Gypsies is only one tenth of that found amongst other Bulgarians. Similarly, prevalence in the U.S.A. differs according to race, with Hispanic, then White, then Asian, then Black people being more prone. It is also important to realise that different studies give different results – thus the figures cited here for England & Scotland differ from those reported by PUK above. These figures should be treated as contextual material rather than incontrovertible facts.

	2009	2009	2020	2020
Age Group	Population	Estimated Parkinson's prevalence	Population	Predicted Parkinson's prevalence
20-39	16,567,286	402	15,820,000	384
40-59	16,639,732	7,978	15,000,000	7,192
60-79	10,987,129	69,833	16,900,000	107,415
80+	2,837,809	48,678	2,750,000	47,172
Total (over 20)	47,031,956	126,893	50,470,000	162,165

Table 22 Predicted Parkinson's prevalence for 2020

This table is based on 2009 estimated Parkinson's prevalence and population trends in the UK.ⁱ

^h Statistics collated by <http://viartis.net/parkinsons.disease/prevalence.htm>. Accessed April 2013.

ⁱ Table taken from p. 10 of 'Parkinson's prevalence in the United Kingdom' (2009)
See: http://www.parkinsons.org.uk/sites/default/files/parkinsonsprevalenceuk_0.pdf

Appendix 9: 'It impinges on your human rights'

Sheila (44/53), travelling home by train, explains: 'I didn't have a seat, I didn't want one because I was in one of these 'can't stop moving' ... spells... umm, so I was actually standing up which was better for me and I was wriggling around, you know, and I, I, I just had to sort of really, when I said my muscles need stretching so I was, I suppose I was pulling all these different poses, just trying to stretch my muscles, and there was a group of, umm, young college kids on and, umm, I couldn't really see where they were because it was, like it was dark and there were just reflections in the windows, you know, it was quite difficult to see who was where, but I could hear them saying "*Oh, she must be drunk*" and this and that and, you know, making remarks. And if I could see have seen them, who it was, I would have said something, you know, but I couldn't ...and I couldn't be bothered to just say it to anybody. That was really bad, really bad experience, you know, sort of, umm... Just wanting people to know that I'm not stupid and I'm not drunk and...**J: What would you have said to them?** 'Umm, I think I would have said "actually I've got Parkinson's disease and I'm in a lot of pain at the moment" and that would have been it, you know, just explained it to them.'

Michael (46/65): 'I remember being escorted out of all these wine bars or pubs or anything, I don't think there's anywhere I haven't been and all the protesting in the world doesn't change their minds. Black cabs won't stop because in London they think you're drunk. And even if they do stop for you, when you start to speak, the slur just makes you sound drunk. So they drive off. I was in London not so long ago and the police came up to the person I was with and said, '*Is this chap annoying you madam?*' because I couldn't walk properly. And I sounded drunk. It's a range of things, you know, that occur in addition to the physical side of ... through the day really. Just to pick up a glass of water takes every resource the human condition can muster really. It impinges on your human rights every second of the day.'

Zoe (29/36): 'People are ignorant, they don't understand what Parkinson's is [...] I'm driven to try and educate those people just so that people like me don't have to suffer with the stigma, or the, umm, lack of understanding, the ignorance of other people...Cos I've been to weddings where people have thought I'm drunk, I've bounced from table to table to table just on the way to the loo. I've walked into door frames and that's *before* I've had a drink. So then I'll have a drink to mask the fact I haven't had a drink ...and then bounce from table to table to table (laughter). But at least I've got the excuse then!'

Appendix 10: ‘Atlas of neurology’

The mystery inherent in neurological conditions such as Parkinson’s has been strikingly captured by Helmut Dubiel.^a In the opening chapter to his book, “Deep in the Brain,” he paints a memorable picture of the area responsible for his suffering:



“In an atlas of neurology, the various provinces of the brain are represented in much the same way as the regions of the earth on a geographical map. Deep within the brain, about where the cerebrum tapers into the brain stem, we find the so-called substantia nigra,^b the “black substance.” Leading from the “black substance” to the neighbouring area called the striatum^c is a narrow band of tissue only a few centimetres long. The striatum is the [receptor] of dopamine, one of the brain’s messenger chemicals that is responsible in the human building plan for controlling and co-ordinating the body’s musculoskeletal system. This region of the brain, which is no larger than a walnut, controls the infinitely complicated interplay of the muscle groups that is required, for example, for a person with an awareness of her own dignity, to stride vigorously and elegantly through a ballroom – much the same as the showman in a pedestrian zone, who becomes rigid like a statue, is only able to perform by virtue of the neuromuscular control required to co-ordinate the ever-changing sequence of excitatory and inhibitory impulse.”^d

(Dubiel 2006, p.1)

^a Helmut Dubiel is a German sociologist who was diagnosed with Parkinson’s at the age of 46.

^b The substantia nigra is where dopamine cells are produced.

^c The striatum is responsible for balance, control of movements, and walking. It is a receptor for the dopamine cells produced in the substantia nigra.

^d Excitatory neurotransmitters: These types of neurotransmitters have excitatory effects on the neuron, i.e. they *increase* the likelihood that the neuron will fire an action potential. Some of the major excitatory neurotransmitters include epinephrine and norepinephrine. Inhibitory neurotransmitters: These types of neurotransmitters have inhibitory effects on the neuron, i.e. they *decrease* the likelihood that the neuron will fire an action potential. Some of the major inhibitory neurotransmitters include serotonin and GABA (Gamma-aminobutyric acid).

Appendix 11: Aetiology of Parkinson's disease

'The aetiology of PD is often explained by environmental and genetic factors, with a postulated interaction between them. While perhaps partially correct, this is an ill-defined way of determining the cause of PD. Environmental or epidemiological studies have identified significant *risk factors* for PD, such as the exposure to pesticides, or *protective entities*, such as cigarette smoking and caffeine intake. They have not helped with the identification of the primary mechanisms that underlie neurodegeneration in PD. However, we should not forget that it was clinical and epidemiological observations that led to the discovery of the nigral toxicity of MPTP and the neurodegeneration caused by paraquat' (Jenner, Morris et al. 2013, p.6).

'Although genetic and experimental models have contributed to exploring the causes, pathomechanisms, and treatment options of PD, there is still a lack of an optimal animal model, and the aetiology of this devastating disease is far from being elucidated' (Jellinger 2012).

Bill (73/78): 'I blame my catching the disease or suffering from brain cells dying on the mobile phone. So they've been around a long time and I attribute my condition to that, rightly or wrongly.'

Zoe (29/36): 'Although there wasn't really a mental trauma breaking my wrist, I think there was a physical trauma and for me – I don't know if this is physiologically possible, but... putting my hand down on the ground after dislocating my ankle which made me fall in the first place- I believe sent a shock wave up my arm and short-circuited my brain ... But whether that's medically possible I don't know, but that's my belief is that, that's what happened, **J: Mm hm.** 'And that my brain didn't know how to cope with that, and so... adrenalin then kicked in...and I think there's some research done on the fact that adrenalin can then start to poison your systemand then you're sort of living on adrenalin. And that's why...you find that a lot of people living with Parkinson's are adrenalin junkies; they're seeking out adrenalin and high adrenalin activities....'

Philip (55/59): 'He puts it down to sheep dip entirely because it's one of those things that can have that neurological effect so, but I'm not so sure that it's that obvious. But it would be ... if it was proved to be so because most farmers have got some sort of deterioration of handling sheep dip and such like. So, yes, it's one of those things that he's convinced is the only cause that he can think of and he might be right, he might not, I don't know.'

Rory (46/48): 'It's natural inquisitiveness to try and trace the root cause to your condition. I worked in the chemical industry for about five years, seven years in fact, I worked for X [...] So could my involvement with chromium, for example, which we used, have been a

factor in my diagnosis, in catching it? I don't want to say 'catching the disease,' ... **J:**
Developing? 'Developing the condition, yes, right. You know there was a variety of
chemicals we used – magnesium, it shouldn't be magnesium, that's an earth metal, but
things like chromium certainly, iron, things like that. Those lead you to wonder whether
they had an impact.'

Michael (46/65): 'I just think I've got this and I just get on with it. **J: So have you ever
tried to attribute it to anything?** 'Well the general philosophy is that first of all we have a
weak gene and that's easily triggered by trauma or toxins. (He then explains that in his job
he went into the roof of a building...) 'I went up there and the sniffers had been up there to
say it was safe, but about ten feet away, one laboratory cabinet vented to air, through a stack
pipe coming up. And just knocked me sideways for a few days. I was just breathing in this
toxic gas. So it might have been that. (He then considers an alternative): 'It might have
been – I was hit in the back by a , hit in the back by a 54 seater coach that lost control and
skidded 70 yards, in X, down a hill. (He also has statistics to hand): Yes it's not a hereditary,
in this country it's hereditary in less than 5% of cases, which is statistically discounted.

Charles (78/82): 'I think of another phrase that Jung used, he said 'Our Gods are our
illnesses, they walk into our lives unbidden, they have a sort of sovereign sway', umm, and I
think that's, that's helped me to a certain extent to realise that it's not, not entirely my fault
that people say you know you've lived a..a you haven't been looking after yourself, or you
haven't been taking this diet, or you haven't been doing this exercise or you haven't been
doing this, er, whatever regime you would deem helpful for health. But whatever you do, it
all comes down to the same thing – there's still that contingent element in it, which, er, you
can't avoid.'

Appendix 12: Representations of Parkinson's

Scientific papers

1. 'Parkinson's disease is a progressive neurodegenerative condition. There is an increasing incidence and prevalence with advancing age and more cases are predicted as the population ages. Because of likely differing aetiology, genetics and pathology in individual patients, as well as confounding co-morbidities, diagnosis can be difficult even for specialists' (Macphee 2012).
2. 'Parkinson's disease (PD), one of the most frequent neurodegenerative disorders, is no longer considered a complex motor disorder characterized by extrapyramidal symptoms, but a progressive multisystem or—more correctly—multiorgan disease with variegated neurological and non-motor deficiencies' (Jellinger 2012).

Qualitative articles

1. 'Parkinson's' Disease (PD) is a chronic neurodegenerative disorder. Although aetiology remains largely unknown, possible contributory factors include stress induced neurotoxicity and there is some evidence for a genetic link [...] The characteristic features of PD are tremor, rigidity, postural instability and slowness of movement (bradykinesia) [...] Treatments to replenish depleted dopamine have been fairly successful in controlling these physical symptoms. However, prolonged use of such medication can produce side effects of further motor problems such as dyskinesias (involuntary movement)' (Bramley and Eatough 2005).
2. 'Parkinson's Disease (PD) is an incurable progressive neuropsychiatric condition with motor complications. In the United Kingdom (UK) approximately 120,000 people are currently diagnosed with PD, with 10,000 new cases each year, with incidence rates highest amongst older people. The majority of people with PD live in the community and are cared for by family members, typically aged over 65 years' (McLaughlin, Hasson et al. 2011).

Charities

1. **UK:** 'Parkinson's is a progressive neurological condition. People with Parkinson's don't have enough of a chemical called dopamine because some nerve cells in their brain have died. Without dopamine people can find that their movements become slower so it takes longer to do things. The loss of nerve cells in the brain causes the symptoms of Parkinson's to appear. There's currently no cure for Parkinson's and we don't yet know why people get the condition.' <http://www.parkinsons.org.uk/content/what-parkinsons>
2. **Europe^a:** 'Parkinson's disease, or PD as it is sometimes referred to, is a progressive, neurological condition. It is predominantly characterised by difficulties with body

^a The EPDA is the only European Parkinson's disease umbrella organisation. It represents 45 member organisations from 36 European countries and advocates for the rights and needs of more than 1.2 million people with Parkinson's and their families.

movements, known as ‘motor symptoms’ – the most identifiable, perhaps, being tremor. Other difficulties that are not related to movement can also occur, such as pain, sleep disturbance and depression - these are known as ‘non-motor symptoms’.

<http://www.epda.eu.com/en/parkinsons/in-depth/parkinsonsdisease/>

3. Ireland: ‘At its simplest, it is a progressive* neurological disorder, which so far cannot be cured. It is variable in its progression, i.e. some people progress more slowly than others, and the symptoms can be effectively controlled with medication for many years. Parkinson's results from a shortage of dopamine, a chemical that helps instructions from the brain to cross from one nerve cell to the next, in a part of the brain called the substantia nigra, which has to do with controlling movement.’ (*progressive = getting worse over time)

<http://www.parkinsons.ie/>

4. U.S.A.: ‘Parkinson's disease is a chronic, degenerative neurological disorder that affects one in 100 people over age 60. While the average age at onset is 60, some people are diagnosed at 40 or younger. There is no objective test, or biomarker, for Parkinson's disease, so the rate of misdiagnosis can be relatively high, especially when the diagnosis is made by a non-specialist.’

<https://www.michaeljfox.org/understanding-parkinsons/i-have-got-what.php>

Newspaper articles: Headlines

1. ‘*Parkinson's has hit my family.... but we'll never let it wreck our lives: Cake-baking star Jane Asher refuses to be crushed by the cruel illness*’ (Daily Mail, 13 April 2013).
2. ‘*Graham Norton: My father couldn't fight Parkinson's*’ (Daily Express, 22 April 2013).
3. ‘*Dad's Parkinson's drove him to suicide – but I won't let mine destroy my life. Sky presenter Dave Clark bravely goes public with his devastating diagnosis*’ (Daily Mail, 24 June 2013).
4. ‘*The doctor said: ‘Hi, you've got Parkinson's.’ His plan to race 156 miles was dashed by a shock diagnosis. Since then, Alex Flynn has run 6,200 miles.*’ (The Times, January 29, 2013).

Wikipedia: ‘Parkinson's disease (PD, also known as idiopathic or primary parkinsonism, hypokinetic rigid syndrome/HRS, or paralysis agitans) is a degenerative disorder of the central nervous system.’

http://en.wikipedia.org/wiki/Parkinson%27s_disease

Table 23 Different representations of Parkinson's

Appendix 13: Non-motor symptoms

Speaking on the Radio 4 Programme ‘Inside Health’ in February 2013,^a Professor Ray Chaudhuri^b was keen to bring non-motor symptoms in Parkinson’s disease (PD) to a wider audience. Non-motor symptoms are typically thought to occur in advanced PD but he is keen for people to realise that they also occur at the untreated and pre-motor stage. For example, estimates suggest that a reduction in the ability to smell may take place as early as 15-20 years before diagnosis or, on the conservative side, 10 years. He commented that many doctors are [still] not alert to non-motor symptoms. In the early phase such symptoms may include:

<p>Sleep problems:</p> <ul style="list-style-type: none"> ○ Insomnia ○ REM behaviour disorder ○ Falling out of bed ○ Talking in sleep ○ Acting out dreams ○ Daytime sleepiness 	<p>Other problems include:</p> <ul style="list-style-type: none"> ● Loss of sense of smell ● Constipation ● Depression <p>Pain</p> <ul style="list-style-type: none"> ○ Usually on one side of the body ○ Often in the limb that later shows signs of PD
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In Chaudhuri’s words, the treatment and management of PD [in the UK] is ‘*still not very robust.*’ He also explained that whilst dopamine neurone loss remains a key factor within Parkinson’s, research is revealing that other areas also deteriorate. For diagrams relating to the different areas of the brain affected by PD, see:

<http://www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Quick-links/Seminar-Slides/Seminar-6/Ray-Chaudhuri.pdf>

^a <http://www.bbc.co.uk/programmes/b01qjb1t> : The discussion starts at c. 21 minutes and 18 seconds.

^b **Biographical details:** Professor K Ray Chaudhuri MD FRCP DSc is Professor in Neurology/Movement Disorders and Consultant Neurologist at Kings College Hospital and Kings College London, an Academic Health Sciences Centre, and also principal investigator at the MRC centre for neurodegeneration research at Kings College, London. He is the medical director of the National Parkinson Foundation International Centre of Excellence at Kings College, London. He sits on the Nervous Systems Committee of UK Department of Health, National Institute of Health Research) and is currently serving as the member of the scientific programme committee of the MDS (2013-2015). He is the Chairman of the newly formed Movement Disorders Society non motor study group. Amongst other things, he serves in the clinical advisory group of Parkinson’s UK and is an advisor to the European Parkinson’s Disease Association.
<https://kclpure.kcl.ac.uk/portal/en/persons/kallo1-ray-chaudhuri%28fa1be0c9-c0bb-4f73-903b-07fbbbf13779%29/biography.html>

Appendix 14: Official list of symptoms^a

Listed on the first page of this appendix are the features essential for a diagnosis of Parkinson's as well as the associated symptoms that may precede or follow on from a diagnosis of Parkinson's. The second and third pages outline the actual symptoms experienced by 12 of my participants, as described to me during their interviews. The list below is taken, with thanks, from the lecture given to medical students by the Parkinson's specialist nurse (June 2012).

Essential Features:

Bradykinesia and one, or more, of the following: tremor (resting); rigidity; postural instability

Additional Features:

- Postural hypotension
- Shuffling gait
- Reduced arm swing
- Difficulty in swallowing
- Monotonous (quiet) tone of voice
- Micrographia (small handwriting)
- Risk of falls increases
- Mental and cognitive disturbance (including dementia)
- Vivid dreaming (REM behaviour)

Other associated symptoms

Depression	Daytime somnolence	Dry eyes	Seborrhoea
Apathy	Insomnia	Sialorrhoea (excessive saliva)	Weight loss
Anxiety	Pain	Dysphagia	Weight gain
Attention deficit	Paraesthesia	Dysphonia	Hypersexuality
Delusions	Olfactory disturbance	Nausea	Loss of thought
Obsessional behaviour	Sweating	Constipation	Bradyphrenia (slowness of thought)
Confusion	Urinary urgency	Faecal incontinence	Word-finding problems
Hallucinations	Sexual dysfunction	Fatigue	Restless Legs Syndrome
Panic attacks	Falls	Diplopia (double vision)	
	Ahedonia (inability to experience pleasure)	Dystonia	

^a For an extensive and comprehensive list of motor and non-motor symptoms, usefully grouped into categories, please see pp. 31/36-39, Chaudhuri, K. R., et al. (2011). Fast Facts: Parkinson's Disease. Abingdon, Health Press Ltd.

Participants' symptoms

I have chosen the symptoms as described by six men and six women in order to represent different lengths of time since diagnosis (1 year to 18 years). The symptoms are listed in the order in which they emerged during each person's interview.

Male Participants

2y	5y	5y	6y	11y	18y
Left hand slower	Tremor	Fibrillation in finger	Slowing right up	Problems with right arm	Immobile arm
Difficulty getting in and out of car	Handwriting	Speech, voice affected	Thinking process slowing	Slow	Tremor
Problems turning over in bed	Loss of balance	Narcolepsy	Not feeling well	Freezing	Dragging leg
Incorrect posture Leaning to one side	Walking difficult	Shaking in lower limbs	Bladder infection	Loss of balance	Dyskinesia
Sagging shoulder	Falls	Stoop	Dodgy balance	Falls	Nausea
Walking	Loss of confidence	Depression	Loss of concentration	Hands not working	Restless legs
Loss of confidence	Voice problems	Pain and muscular stiffness	Lethargy	Mycrographia	Loss of co-ordination
Wrong timing (meetings etc.)	Reading problems	Falls	Constipation	Immobile (wheelchair)	Falling
Burning sensation in back		Mycrographia	Stiffness	Not sleeping well	Freezing
Reduced interest		Mask like face	Back pain	Urgency (toilet)	Shuffling gait
Anxiety		Tendency "to go slightly high"	Insomnia	Tiredness	Appearing drunk
			Nightmares	Poor memory	Slurred speech
Nervous/apprehensive			Shuffling gait		Depression
Voice problems			Leaning to one side		OCD
Lack of sleep					No strength
Sexual problems					Unable to walk (wheelchair)
Sensitive to noise - easily startled					
Emotional					
Excessive sweating					
Sleepiness					
Lack of co-ordination/rhythm					

Table 24 6 male participants' symptoms and number of years since diagnosis

Female participants

1 y	2 ½ y	8y	9 y	10y	10y
Handwriting/ Mycrographia	Shaking hand	Fatigue	Uncontrollable shaking	Shaking leg	Tremor in feet
Walking – “slapping foot down”	‘out of control’ – juddering	Lack of energy	Handwriting – smaller (mycrographia)	Claw toes	Stress
Fumbly (fingers)	Aches and pains	Drop in fitness	Difficulty using cutlery	Frozen shoulder	Limping
Poor balance	Depression	Hand shaking	Fatigue	Veering to the right	Writing smaller
Lack of strength	Nightmares	Difficulty speaking	Walking ‘oddly’	Worried, anxious	Risk of falling
Walking limited	Very tired	Limping	Arm not swinging	Falling	Mobility problems
Fatigue (day)	Constipation	“losing control of myself”	Stiffer	Unable to turn over	Freezing
Insomnia (night)	Diarrhoea	Loss of sense of smell	Slower	Walking deteriorated	Tiredness
Slight tremor	Unsure where feet are in relation to ground	Stumbling over words	Unable to get out of bath	Aching limbs/muscles	Poor balance (need for wheelchair on occasions)
Stress	Lightheaded	Light headed	Depressed	Emotionally drained	Cautious in crowds
Speech – slurring	Writing Mycrographia	Depression	Hallucinations	Fatigue	Fear of being knocked over
Feeling emotional	Fingers ‘stick’	Difficulty walking	Dyskinesias	Freezing	Unpredictable moods
Poor balance	Foot problems	Hallucinations	Insomnia	On/off	Nauseous
Anxiety	Cramping	Easily startled	Shuffling gait	Tearful	Sweaty
	Anxiety	Anxiety	Getting around on knees	Voice quiet	Curvature of spine
		Inability to read/concentrate	Joint pain	Head tension	Bladder and bowel problems
		Emotional	Muscle discomfort	Restless legs	Urgency
			Appearing ‘drunk’		Muscle tension
			Generalised pain like a ‘toothache’		Back pain
			Anger		Difficult to turn over
					Fumbly fingers
					Stiff
					Posturing (hand)

Table 25 6 female participants' symptoms and number of years since diagnosis

Appendix 15: Participants' drug regimes

'I'm always amused by people who say "shifts in regime" when what they actually mean is more tablets, more capsules'
(Julian, 54/49)

Before giving voice to a number of participants' descriptions of their drugs, I wish to let Sheila speak, for she captures both the intensity of the experience as well as Sarah's view that *'nothing is straightforward'* about the drugs. Before the interview, Sheila mentioned that she was coming to the end of 'the honeymoon' period with her drugs. It feels important to allow her to speak, unedited.^a

Jane: So, how...how have things changed for you...since diagnosis?

Sheila: 'Well, I suppose, I suppose as you need...the thing is, is that it's been **gradual** – umm – and it, it er, **lurching** as well. It **lurches**..., so ...when you first start your medication you're going to get **thrown all over the place**, you don't know what you're doing, you know, you're really out, **out of kilter, sort of mentally and physically** because your body's just... **walloped** with all these drugs...umm, then you get on to, you know, it all **figures itself out**, you might have to **adjust the dosage and timing** and things like that, which takes some time to do, and then you get like a, like you're **on a plateau** for a while - and in the beginning it was sort of like, for **a year, 18 months**, something like that, you carry along quite nicely, you'd be **quite pleased** with the medication, you'd be acting **almost normally** but not quite, you know – er, you'd **seem to be** acting normally but it would feel...very **different**, you'd still be **very tired**...umm, and I understand that it can take up to **4 times as much energy** to do something as it would normally so it's quite a lot, gosh quite a lot- yeah. Umm, then you come to a, a, the point where the medication isn't as, as effective any more, it **wears off**, so it has to be **adjusted**, even **increased** or **different medication** tried ... then you go through **another wobbly** period where you're **all over the place** adjusting to it... and so you can **go down and then up**... and then you reach **another plateau** and it seems like that all the time. So every time the plateaus are going down but there might be a little, you know, a little upper for a while which is, which is always good. But when the medication starts not working you know you're in for a **rocky patch** you know,

^a As can be seen from the density of the transcript, the issue of medication is one of profound importance to Sheila. Words in bold highlight what, to me, seem to be key aspects of her experience.

which can take maybe **6 months to sort out** that seems a long time...it is a long time. It's not always, you know, but my experience lately is that it takes that long, yeah, yeah...and I've ended **up in hospital** through **side effects** of medication I think ... about 3 or 4 times. Yeah.'

J: How long for? 'Usually just overnight you know, but it has been quite, it's been **very distressing** actually' **J: Mmm** 'Yeah... yeah.'

J: And do you have to take medication to alleviate some of the side effects?

'Yes, that's it - I mean I try not to as much as I can, umm, but yes, it can be like that, yes, yes....' **J: Gosh** 'Yes, yes. And it's, it's **mental as well as physical** you know, I

mean one of the times I had, I was having **hallucinations** and er, yes, very strange.

And I was writing things that **didn't make sense**... you know I'd start off at the top of the page and it would be perfect and by the end of the page it was just rubbish.

Actual words but it didn't make any sense...umm...it's also been **visual**

hallucinations as well, umm, but sometimes I couldn't, I **couldn't keep still for 8**

hours at a time, you know, and I just, just **wanted to be sedated**, you know, just to

keep still, so tired, yeah, yeah...went off in the ambulance. They couldn't keep me

still (slight laugh), you know, and er, there was nothing they could do about it... go

through it... that's right, yeah, yeah... It's just ...**it's unknown** every time you take

something you **don't know what effect** it's going to have...and, umm, lots of

people, umm, no, not lots, some people have you know really **bad compulsion**

disorders and things. And a friend of mine got into **gambling** and you know there's

sex addiction... all manner of things come up and yeah, that's something I've sort of

asked my friends to look out for and touch wood I don't think I've had anything like

that - umm.... **Insomnia, it's awful**. Really bad, umm, but you do get used to that,

I think your body adjusts, you know, and some other people, like Margaret Thatcher,

she did run, run on very little sleep, I think that's, that doesn't bother me so much

now.' **J: Mmm**. 'But there are times when I'll have **a drink and sleeping tablets**

to knock myself out - umm, the consultant knows I do it, and that's maybe, maybe

3 or 4 times a year, but sometimes you just need, you know, **to blot out**

...yeah...yeah...mmm...'

I remember my surprise, even shock, at this coda to Sheila's description of her medication, and in my notes I wrote that this was 'something that doesn't seem to square with the woman in front of me.' I mention this now as a reminder that, despite actively working to suspend judgement, human frailty is such that I had clearly started to build up my own characterisation of Sheila by that stage of the interview.

'They're just a ritual' vs it's 'tyrannical'

Julian: 'I calculated the other day [...] Since I've been diagnosed I've taken 4408 either tablets, patches, pills or capsules or whatever umm, and presumably, by the time I'm called home, as it were, it'll be, umm, goodness knows how many thousands. I, I, they're just a ritual, just in the same way you brush your teeth, you take your tablets. Simple as that. It's not a big deal. Side effects, I've generally done pretty well with them. A lot of people have very bad side effects, I on the whole don't. Umm, sometimes feel a bit sick, umm, pretty much it, really.'

For **Zoe**, brought up to go to school whether or not she was poorly, taking drugs is a big deal: 'How do you then go from that (taking a couple of paracetamols) to then having to take drugs ...you know, tyrannical way of taking, you know you must take them at these times, and these times of these days, which means you have to get out of bed at certain time in the morning to take ... to hell with that! You know, if I want to get up or if I want to have a lie in, then I'll have a lie in, I'll take my drugs when I get up. And... I've got to the point now, umm, it wasn't until probably about 6 to 12 months ago, I can't remember the exact moment of clarity, umm, I remember a PD nurse said '*Do you realise you could die if you don't take them properly?*' (Listening back I realise I must have had a horrified expression on my face...) 'That was my reaction as well...' (Nervous laugh) **J: What, what would happen?** 'You can go into what's called neuro... malignant, neuroleptic shock'^b **J: That sounds horrible ...** 'where it sends your organs into organ failure.'

Rory: 'I'm on REQUIP XL ropinirole. And that's fine as far as I can make out, and therein lies another tale. Of course you start off at point 0.75mgs per day and nobody tells you what you're expected to go up to. So when you come off the starter pack which takes you up to 4mgs I believe, or round about that, or maybe 3,

^b Malignant Neuroleptic Syndrome or Neuroleptic Malignant Syndrome. For information about this syndrome, see : <http://www.patient.co.uk/doctor/neuroleptic-malignant-syndrome>

4.5, whatever, per day, you think by the end of that starter pack you're well and truly into the medication. I've been led to believe you don't really feel any effect until about 12mgs. So currently being on 14 was a bit of an eye-opener. I didn't expect to go that high, that quickly, if that makes sense.'

Adam: 'I started with Requip on a very low dosage and gradually increased **J: Right** 'Until I was eventually up to ...16 milligrams of Requip which was a, a longer lasting, XL type ...medication and that seemed to do quite well, kept me under control most of the time. (Adam's delivery is lacking in flow – slight hesitant sounding pauses punctuate it) And then I had reason to go to - I, I in the meantime I'd been referred to, umm, X who's the Parkinson's nurse [...] who's absolutely brilliant, and she suggested that she could help me more by introducing another drug, Madopar, which [I] would take three times a day, so again started off with a low dose and then up to about - I think they're 125 each tablet and I take those 3 times a day' **J: Right** 'But the XL ones, the Requip, I only take once a day, still 16 milligrams.'

Philip: 'So medication was increased slowly from, you know, point .05 right up to, I ended up with 24, which is maximum. That was, you know, improving the symptoms and such like, but I started getting side effects from the high dosage, so...'

J: What sort of side effects? 'Well principally swollen ankles and not sleeping was a problem and various other little things. And dreams that were realistic, too realistic sort of thing, confusing you as to what was real and what wasn't and such like. So they put me down to the Sinemet and reduced the dose to half on the Ropinirole. And since then I've gone on to Stalevo, which is levodopa, carbadopa and entacapone. And I'm still on Ropinirole as well. So that's my basic doses.'

J: So how many tablets is that altogether in a day? 'Well, the Ropinirole has been changed to once a day treatment. So it's a slow release, which is working quite well, because, you know, I feel that I'm, you know, more stable. I'm on 14mgs a day now. But that comes in three tablets, two of four and eight – but they don't do in-between sizes, so you have to have three to deal with one treatment. So, those [I take] first thing in the morning. And then I have Stalevo which is the levodopa, carbadopa mix, which I have four times a day, one in the morning, lunchtime, evening and last thing at night.'

Appendix 16: Deep Brain Stimulation (DBS)

As discussed in Chapter 4, nearly all participants framed any talk of medical research in terms of a cure. Talk of medical research also prompted many participants to voice their views about deep brain stimulation (DBS). For two participants in my study, DBS had become their only option after reaching a stage where drugs no longer offered effective treatment. Both looked upon DBS positively, even though one participant had traded clarity of speech in order to regain the ability to walk. For the remaining participants, contemplating deep brain stimulation revealed considerable existential challenges, further compounding those exposed by the absence of any cure. Whilst participants' attitudes towards DBS varied in nuance, they were all united in their sense of relief: the relief that their disease had not yet reached a stage that required them to consider DBS in earnest which, in turn, allowed them to take refuge in a 'narrative of postponement.'

Julian (54/49): For Julian, DBS is high risk but he has not reached a stage where he needs to make a decision about it:

'There is a school of thought that suggests deep brain stimulation should be given earlier than later in the course of the illness. The argument is based on the philosophy that you can only enhance what function there is and if you do it early on in the condition you buy yourself a lot more, you buy yourself essentially 5 more good years rather than buying yourself 5 more better than they were but still not brilliant years later on. Balanced against that is that the umm, the risks from DBS are pretty high in my view. Umm, I think they talk about catastrophic strokes in approximately .3 – I, I would have to check my figures on this – but it's somewhere in the region of .3% - that's 1 in a 1,000. So in that respect – which may not seem much, but that's 1 in a 1,000, umm, whose life will be basically over if they, because it goes horribly wrong, they have a stroke, etc. Er, and at the moment, it is all a case of cards you throw out of a pack - to my mind at the moment that's too high a risk to consider it - I may think differently further down the road.'

Sheila (53/44): Like Julian, Sheila also surmises that she 'may think differently further down the road' thereby acknowledging the adaptive nature of humans to any predicament they may face. Nevertheless, she retreats into the present as she acknowledges that to contemplate DBS is to contemplate a future that she *'just can't see [...] at the moment.'*

'Umm, with deep brain surgery, umm, personally, I just couldn't go down that line at the moment, you know, who knows, I might change my mind.' (I return to this a little later in the interview): **J: You mentioned that at the moment, no, but that you might change your mind?** 'I can't see myself changing my mind, umm...' **J: And what is it**

that...would hold you back? ‘Hold me back?’ (She states very definitely): ‘Oh being awake, being awake ... having, having that done... 8 hour operation. I just couldn’t face it. But, and again, my neuropsychologist has, has talked about this, not just this but lots of other things as well, cos I say ‘oh I don’t know if I could cope with this that and the other,’ you know, the choking and whatever, and umm, she says it’s actually... surprising cos.. All the people she sees sort of say that but she says that in her experience, when people come across those problems they thought they couldn’t cope with, something happens and they, they do somehow adapt. So that’s why I’m not, not ruling it out completely, but umm I just can’t see it at the moment.’

Caitlin (57/46): Like Julian, Caitlin also comments on the risks and, like Sheila, she is fearful of the unpleasantness of the procedure:

‘I mean, I know with DBS there’s a risk of stroke, for example. There’s a risk of haemorrhage as there is with any other surgery. I also know that it’s a lengthy procedure done under local anaesthetic. It would be very, very unpleasant to endure I would imagine.’

Jonathan (72/68): Jonathan is also fearful of any adverse effects and would prefer to allow the disease to take its course rather than be plunged into ‘sudden deterioration’ due to unsuccessful treatment.

‘I’d be a bit more concerned about deep brain stimulation because I feel that’s more problematic. I would have to be convinced that it wouldn’t - as in some cases it can have an adverse effect. And one wouldn’t want to run the risk of having a particularly strong adverse effect. I would prefer to carry on with the score as it is than sudden deterioration due to a problem that arises over that sort of research.’

Angela: (69/68): Just as Jonathan would ‘prefer to carry on with the score’ so, too, talk of DBS prompts Angela to realise how important is it simply to try and stay on an ‘even keel’:

‘I mean I look at some of the, some of the treatments that are talked about, you know, the deep brain stimulation and those sorts of things and I think, well, probably they’re really more for younger people that are diagnosed when they’re young, because in the scheme of things, you know, I’ve had my life and the sort of experimental side of things probably won’t be there for me. Probably I just need to hope to sort of stay on an even keel for as long as I can. And then other times I think, ‘Oh I wonder if I ought to try that.’

Joan (55/52): For Joan, the brain is sacrosanct. Reflecting on the idea of invasive research, she comments:

‘Yes, I do find that a bit frightening really. I suppose it’s just, you know, the layman’s fear of doing something into the brain. There was though, in the last, so I do read it (reference to the quarterly PUK magazine which she has told me she largely ignores) there was a story in the most recent Parkinson’s, of a lady who had had some form of brain surgery or....

J: (I have read the same article) **Oh – did she have deep brain stimulation?** ‘That’s it. That was it, that was it, yes.’ **J: I think she was quite young too, wasn’t she?**

‘Yes she was and [...] Yes, that was it. I didn’t read the article in full, I must say, but I thought ‘Hmm’ – but I suppose yes, it’s a natural worry about what’s in your head isn’t it, really? Yes, I think that would be, I’d put that a long way down the line I think, for me, personally.’ **J: Yes, so seeing the brain as something distinct from the rest of the body?** ‘Well I suppose yes, yes. A bit sacrosanct I suppose.’

Although not actually using the term ‘sacrosanct’ other participants, including Darren, Janie, and Barbara, echo Joan’s view.

Darren (47/46): Darren refers to a BBC 4 programme he has watched featuring Barbara Thompson, a professional saxophonist living with Parkinson’s.

‘There was a bit around stem cells, but deep brain stimulation, I was of the same opinion as her. Unless it was really proved that it was going to work and it wasn’t dangerous, which I know it’s got to be dangerous what they’re doing, unless I was really bad, I don’t think I’d want to have that done because it sounds quite, that’s quite scary having needles put through your brain and stuff. So I’d be squeamish!’

Janie (63/53): A sense of the brain as sacrosanct alongside Darren’s ‘squeamishness’ can be heard in Janie’s narrative. Furthermore, she voices her concern about control. Interestingly, she appears to perceive undergoing the procedure of DBS, rather than Parkinson’s itself, as involving loss of control, whereas for Arthur Frank ‘disease itself is a loss of predictability’ and ‘illness is about learning to live with lost control’ (1995, p.30).

‘I don’t fancy the one where they fiddle around in your brain and you’re awake’

J: Oh, the Deep Brain Stimulation? ‘It’s about 12 hours isn’t it? I suppose it just feels a little bit...I don’t like the dentist, it’s all to do with your head.’

J: Do you think, were it something though that, say your consultant said, ‘Look Janie, your Parkinson’s is at such and such a stage, this might help?’ ‘[It] might help. I suppose when you say it like that you think, well, I think, I’m not that – the one where you’re awake and they.... The injection one doesn’t sound so bad. Once again, they put things in – it’s about being out of control isn’t it? Not being in charge of yourself, and I

think if your brain is not functioning properly you don't feel as if you – I mean, mentally I feel in charge of myself, but...'

Barbara (72/70): Barbara spends time trying to rationalise what it is that holds her back, despite evidence that suggests DBS is 'producing a lot of very good results':

'I would have to think very carefully about having surgery on my brain or a surgical procedure that involved my brain. I mean certainly if – the work on that area is deep brain stimulation area, continues, it does seem to be producing a lot of very good results and I can see that there could be a time when, it's not there yet, but when I reached a point where I felt that I really could benefit from it and then I, it's strange because I have had to have several bouts of surgery for various problem. And the only one that really caused me a difficulty was having a lens replacement for a cataract. And that was because I didn't like the thought of somebody interfering with my eyes. And I think I'd feel the same about the rest of my brain too, you know, although obviously it's a bit of my brain that is not, for chemical reasons, functioning as it should.'

Charles (82/78): Charles, on the other hand, is not only aware that he is '*not as seriously afflicted as many people with Parkinson's*' but has also reached an age whereby talking about DBS is to indulge in his love of all things technological:

'In particular I'm fascinated by... the umm... operation in which they put a wire through to the brain stem, umm, forgotten what they call it' (his voice fades as he tries to remember what it is called) **J: Is that the deep brain stimulation?** 'Deep brain stimulation, that's right - they do that in X. Mind you I haven't asked for it and I haven't been offered it, umm, I'm just interested in case, and whether they would allow me to have it at my age on the NHS, because it's a very expensive operation. I don't know, and I'm not even sure I would want it, but...(takes a breath) technologically minded as I am, you know they supply you with a, a remote control which switches the tremors on and off' (there is laughter in his voice) 'using something like a, a kind of...umm...pacemaker, but under the skin, or 2 pacemakers...do the necessary switching...umm... but I've only read about that and heard a lecture on it as well.'

Richard (60/59): Finally, Richard's views are an interesting illustration of the degree to which others' stories have the potential both to influence and clarify one's own story. Having also watched the programme about Barbara Thompson, it is possible to hear how her story allows him to embrace a narrative of postponement:

‘I suppose because I’m so early in the...the stages, and in – I don’t know if it’s formally known as a ‘honeymoon period’ but I’m in a honeymoon period and, umm, the thought that she, she was diagnosed with Parkinson’s some time ago, so again, my immediate thought is ‘I’ve still got quite a bit of time before this really starts to, er, to grip.’

He is acutely aware that his situation will change and allows further stories to seep into his consciousness whilst nevertheless retaining the hope that his condition will continue to respond well to treatment in tablet form:

‘... I’ve thought about this – not as an immediate prospect, but I’d rather have the drugs... the thought of having something implanted in your brain... rather gives me the collywobbles. It’s interesting that Barbara Thompson decided not to go for it, but on the other hand there’s a guy at the Parkinson’s group, and he’s the leader and very articulate - he doesn’t really look like a Parkinson’s sufferer, but he must be quite advanced because he’s had deep brain stimulation. I mean it’s continuous, isn’t it, it’s not just one ...implant? So I’m sure my attitude will change if and when the Parkinson’s gets worse, but yeah, I prefer something in....tablet form!’

BSMS Research Governance & Ethics Committee (RGEC)

Chair: Professor Kevin Davies

Deputy Chair: Professor Bobbie Farsides

Secretary: Miss Caroline Brooks

Tel: 01273 872855 c.e.brooks@bsms.ac.uk

Applications and general enquiries: rgec@bsms.ac.uk



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01/07/2011

Professor Bobbie Farsides
Brighton and Sussex Medical School
Medical Teaching Building
University of Sussex
Falmer
Brighton
BN1 9PX

Dear Professor Farsides

Full Study Title: To try or not to try? Patients views on cutting edge research in neuroscience

RGEC Ref No. : 11/066/FAR

I am writing to inform you that the Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC) has now assessed your application. On our recommendation the University is willing to take on the role of **Research Sponsor** for the duration of the study.

Your project has been allocated the following reference: **11/066/FAR** please quote this on all correspondence.

Conditions of Approval

Please note that you cannot commence this study until you have been given a favourable opinion by an appropriate NHS Research Ethics Committee (REC) (National Research Ethics Service). The approval will cover the period stated in your application to that committee, and will be extended in line with any amendments agreed by the REC.

A favourable opinion must be gained from the appropriate Research Ethics Committee within 6 months of the issue date of this letter. Any delay beyond this may require a new review of the project.

If your project receives an unfavourable ethical opinion from an NRES REC, you must submit the revised protocol to RGEC for sponsorship approval prior to re-submission.

Indemnity

The study will be indemnified by the University of Sussex.

Please obtain the Public Liability Certificate, Employers Liability Certificate and Professional Negligence Certificate which are available from the University of Sussex insurance webpage: <http://www.sussex.ac.uk/finance/services/corporateaccounting/insurance>.

NHS Management Permission (R&D Approval)

In addition to a favourable opinion from NRES you will also need to obtain NHS Management Permission (also referred to as R&D Approval) for each NHS site where you will be conducting the research or recruiting patients.

If your research will also be conducted on University of Sussex or Brighton premises, you will be granted management approval by this committee following notification of a favourable opinion from NRES.

Amendments

Any amendments to the project dated after the issue of this approval letter must also be submitted to the BSMS Research Governance and Ethics Committee for approval in order for sponsorship to be valid. Please submit your application for an amendment to the Committee (via rgec@bsms.ac.uk) using the 'Request for an Amendment Form'.

Monitoring

The Medical School has a duty to ensure that all research is conducted in accordance with the University's Research Governance Code of Practice. In order to ensure compliance the department undertakes random audits. If your project is selected for audit you will be given 4 weeks notice to prepare all documentation for inspection.

It is your responsibility to inform me in the event of early termination of the project or if you fail to complete the work.

I wish you luck with your project.

Yours sincerely



Professor Kevin Davies
Chair of the BSMS Research Governance and Ethics Committee



NRES Committee South East Coast - Brighton and Sussex

NHS Brighton & Hove
Level 4, Lanchester House
Trafalgar Place
Brighton
East Sussex
BN1 4FU

Telephone: 01273 295 490
Facsimile: 01273 574737

08 September 2011

Ms Jane Peek
PhD student
Wellcome Trust funded student
Brighton and Sussex Medical School
University of Sussex
BN1 9PX

Dear Ms Peek

Study title: Patient views on experimental research in the context of
Motor Neurone Disease and Parkinson's Disease
REC reference: 11/LO/1366

The Research Ethics Committee reviewed the above application at the meeting held on 01 September 2011. Thank you for attending along with your supervisor, Professor Bobbie Farsides to discuss the study.

Ethical opinion

1 Members agreed that this was a relevant and worthwhile area to research. They commented that this was a well-written submission and felt that you and your supervisors ought to be congratulated for your hard work and an exemplary submission. It was noted that you had adequately addressed the ethical issues that could arise in a study of this kind.

2 It was noted that home computers would be used for the study and members wanted more details about the use of the home computer. At the meeting, you indicated that though the computer was at home, it actually belonged to the Wellcome Trust (university) and that it would be password protected, with the university as the data holders. Members accepted the explanation provided.

3 Members asked how participants would be recruited. You indicated that the motor neurone disease self-help group was holding a conference and that you intended to put flyers into the starter pack that would be sent to these individuals. It was noted that you had discussed this with the relevant personnel who had agreed to this and had indicated that you could approach them after ethics approval had been obtained. While participants with the Parkinson's Disease, would be recruited from PD-UK. Members were agreeable with this method of recruitment but explained that the flyer needed to be approved by the committee before it could be used.

4 Members asked what you intended to do if you got more participants than required (especially for the motor neurone disease group because of the method of recruitment being used). You indicated that you had not thought about this but explained that you would let them down gently. Members suggested that it may be a good idea to sign-post individuals, as to where they may possibly get further support (i.e. other potential avenues)

even if it was only to talk to someone as they may benefit from this. Members suggested including this information in the flyers to be sent out. Members agreed that the flyer to be used in the mail-out could be submitted as an amendment to be reviewed by the committee before it was sent out.

5 It was noted that you had indicated that you may review some high profile participants and members wondered whether this may make a difference to the results of the study. At the meeting, you explained what you meant by high profile individuals, but explained that you were interested in obtaining diverse views and would welcome and value their input. Members accepted your explanation.

6 Members queried whether two information sheets and consent forms were required for the two groups of participants. They felt that it may be preferable for the two groups to know who was being interviewed for the study. You explained that you had been unsure of this. You explained to the committee that as the trajectories of the two diseases were different and after some research it had been agreed that two sheets would be used. However, you indicated to the committee that you could be persuaded to use a single sheet. Members indicated that they did not feel strongly about this and suggested that you could make a decision after discussion. You indicated that you would speak to the PD or motor neurone disease nurses and seek their views.

7 Members suggested that if you intended to disseminate the results of the study at a conference then it may be a good idea to co-present the findings of the study along with one or more of the study participants. You indicated to the committee that this was an excellent suggestion and would definitely consider it.

Members agreed that the study could be given a favourable opinion as you had responded adequately to all the concerns raised by the committee. However, the committee provided some advice

8 Non-mandatory advice provided:

8.1 Include the words "participant information sheet" above the study title in the information sheets.

8.2 Include the details of the PhD qualification in the information sheets.

8.3 It was pointed out the sheet for "Parkinson Disease" participants mentioned "motor neurone disease" in the section "why have I been chosen?"

8.4 Include the following standard statement in the consent form "I understand that the research data collected during the study may be looked at by individuals from the sponsor organisation, from regulatory authorities where it is relevant to my taking part in the study. I give permission for these individuals to have access to my records".

8.5 Co-present the results of the study during dissemination at conference (as discussed in point number 8)

If you would find it helpful to discuss any of the matters raised above or wish to seek further clarification please contact the committee co-ordinator Mrs Nischinth Cherodian.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		08 August 2011
Investigator CV		08 August 2011
Other: Cv pf Professor Bobbie Farsides		27 July 2011
Other: CV of Dr Catherine Will		29 July 2011
Other: Letter of Invitation (MND)	1	08 August 2011
Other: Letter of Invitation (PD)	1	08 August 2011
Other: Poster (MND)	1	08 August 2011
Other: Poster (PD)	1	08 August 2011
Other: Topic Guide	1	08 August 2011
Other: Letter from Sponsor		
Other: Evidence of indemnity		07 July 2011
Other: Details of proposal - egrant	version 3	

Participant Consent Form: MND	1	08 August 2011
Participant Consent Form: MND - witnessed	1	08 August 2011
Participant Consent Form: PD	1	08 August 2011
Participant Information Sheet: MND	1	08 August 2011
Participant Information Sheet: PD	1	08 August 2011
Protocol	1	08 August 2011
REC application		01 September 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Ms Sue Eckstein declared a conflict - the committee agreed that she would not take part in the discussion but could remain in the room. Dr Simon Walton and Dr Stuart White also declared an interest and it was agreed by the committee that they could take part in the discussion. There were no declarations of conflicts of interests from any of the other members present

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/LO/1366	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely



pp
Dr Simon Walton
Chair

Email: ncherodian@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting
and those who submitted written comments
"After ethical review – guidance for researchers"*

Copy to: *Prof Bobbie Farsides*
Professor Of Clinical and Biomedical Ethics
Brighton and Sussex Medical School
University of Sussex
BN1 9PX
(sponsor contact)

NRES Committee South East Coast - Brighton and Sussex

Attendance at Committee meeting on 01 September 2011

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Jill Adams	GP	No	
Dr Duncan Angus	Consultant Psychiatrist	No	
Dr John Bull	Consultant Physician (retired)	Yes	
Mr Gerard Cronin	Business Development Manager	Yes	
Ms Sue Eckstein	Lecturer in Clinical and Biomedical Ethics	Yes	*interest declared
Prof Angie Hart	Professor of Child, Family & Community Health	No	
Mr Stuart Heatherington	Mathematician	Yes	
Dr Puneet Kakar	Specialist Registrar in Medicine & Geriatrics	No	
Mr Bill Kent	Retired Civil Servant	No	
Miss Samantha Lippett	Lead Microbial Pharmacist	Yes	
Mr Maurice Marchant	Public Health Information Specialist	No	
Ms Nicola Mason	Specialist Midwife - Practice Development	Yes	
Dr Martin Parry	Consultant Paediatric Anaesthetist	No	
Dr Paul Seddon	Consultant Paediatrician	No	
Mrs Kathy Stott	Pharmacist	No	
Dr Richard Venn	Consultant in Anaesthesia & Intensive Care	No	
Dr Simon Walton	Consultant in Anaesthesia and Intensive Care	Yes	In the Chair Interest declared
Mrs Susan Waton	School Librarian	No	
Dr Stuart White	Consultant Anaesthetist	Yes	Interest declared
Ms Debra Young	Head of Midwifery	No	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr Adamu Addissie	Observer
Mrs Nischinth Cherodian	Co-ordinator
Miss Dodie James	Observer

* Ms Sue Eckstein declared a conflict - the committee agreed that she would not take part in the discussion but could remain in the room.



Health Research Authority
NRES Committee South East Coast - Brighton and Sussex

Charing Cross Hospital REC Centre
Room 4W/12, 4th Floor
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Tel: 020 33 10106

26 April 2012

Ms Jane Peek
PhD student
Wellcome Trust funded student
Brighton and Sussex Medical School
University of Sussex
BN1 9PX

Dear Ms Peek

Study title: Patient views on experimental research in the context of
Motor Neurone Disease and Parkinson's Disease
REC reference: 11/LO/1366
Protocol number: N/A
Amendment number:
Amendment date: 02 April 2012

Thank you for your letter of 02 April 2012, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Notification of a Minor Amendment		02 April 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/LO/1366:

Please quote this number on all correspondence

Yours sincerely

A handwritten signature in black ink, appearing to read 'Nischinth Cherodian', written over a horizontal line.

**Mrs Nischinth Cherodian
Committee Co-ordinator**

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