Social Aspects of Communication in Parkinson's Disease:

a mixed methods investigation of the impact of dysarthria on change in social variables.

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Abstract

Background

Parkinson's disease is a degenerative neurological condition which affects motor control, in almost all cases involving speech, and is frequently of many years duration. Much is known about speech production but less of the psychosocial consequences of the speech impairment (dysarthria). Accounts of people with dysarthria have shown that its impact on quality of social participation can be varied and profound. However, level of participation has not been investigated. Reduction in social activity and social networks has been found following onset of other neurogenic communication disorders. In Parkinson's disease there is some evidence of social activity reduction but this has not been studied in relation to severity of dysarthria. Social anxiety has been found to be raised in speakers with other speech production impairments and this may be a contributor to reduction in social engagement. Investigation of social variables is of importance in understanding relationships within a biopsychosocial model of health which underpins intervention for therapies for communication disorders.

Aims

The study aimed to investigate the impact of dysarthria on social participation and whether presence of dysarthria in Parkinson's disease (PD) resulted in changes to social anxiety, social networks and social activity. It further sought to

investigate whether severity of dysarthria resulted in changes to the same variables.

Method

A group of 43 mild-moderately dysarthric speakers with PD were recruited. Exclusion criteria were applied to control for cognitive impairment, depression, apathy, movement disability and co-occurring neurological and communication impairment. A group of 30 non-neurologically impaired participants were recruited matched for age, sex, socioeconomic status and educational attainment. Participants with PD were further grouped using measures of sentence intelligibility and motor speech impairment into higher and lower functioning groups. All participants completed a social anxiety questionnaire, a social activity checklist and detailed their social network. Group data were compared to address the research questions. Semi-structured interviews were carried out with all participants to explore change to social life and perceptions of causes of change.

Results

Participants reported a range of changes to interaction and social engagement arising from speech and other impairments and also from intra and interpersonal contextual factors. Quantitative data showed that presence of dysarthria was associated with social anxiety and avoidance but not changes to social activity level or social network size. Greater severity of dysarthria was

associated with deterioration in social activities and social network. There was wide individual variation on these variables.

Outcomes

Impact of dysarthria may be significant and unrelated to severity of impairment and satisfaction with level of activity is low in dysarthric speakers. Mild - moderately dysarthric speakers with PD may experience social anxiety in particular types of social situation. Moderately dysarthric speakers may experience loss of social capital in terms of quantitative changes in social networks and social activities. Motor speech impairment was a better predictor of social functioning than intelligibility in this sample. It is possible that a threshold for change lies at a more severe level of speech involvement. How speakers with PD perceive and experience their social interactions is discussed and limitations to the research are considered. The implications of the findings are discussed in relation to the ICF framework and the concept of social capital.

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1 Chapter 1 Introduction to the thesis

1.1 Introduction and purpose of thesis

The thesis is intended to document the entirety of a research project which took place over a seven year period investigating some dimensions of social participation speakers with dysarthria and Parkinson's disease. It demonstrates the process by which a research question was identified and investigated and by which the data gathered were interpreted in relation to existing theoretical frameworks. In this chapter, that process is outlined.

1.2 Introducing the research area and focusing on a topic

The project began with understanding that the impact of a particular group of communication disorders (motor speech disorders) was predominantly confined to knowledge of how the disorders affected speech production. Little was known at the time about the psychosocial consequences that dysarthria might have for the person concerned or the opportunities to participate in social situations and relationships. Subsequently, the research topic was focused on particular quantitative aspects of social lives and a range of appropriate variables were identified through study of related literature.

Motor speech disorders may arise from a variety of causes and consideration of the demands of the project logically led to the selection of a single aetiology for recruitment of participants. Parkinson's disease was chosen as this is a disease with high prevalence (243 per 100,000, Hague, Klaffke, & Bandmann, 2005).

If motor speech impairment has an impact on social lives it is logical that more severe impairment is likely to have greater effect. Therefore, speakers with different degrees of speech impairment were investigated. Severity of dysarthria was established using measures of activity and impairment which are discussed in chapters 2 and 4.

The existing literature demonstrates the importance of incorporating the speaker's perspective in order to arrive at a full understanding of the impact of speech impairment on social participation. In order to understand more fully the mechanisms by which speech impacted on participation in this group qualitative interview data were collected and analysed to supplement the quantitative data.

1.3 Objectives of the research

The aim of the research project was to investigate how relationships between dysarthria and social life could be explained.

Specific objectives were

- to test the hypothesis that levels of social participation for a group of people with Parkinson's disease would be lower than those of a matched group of non-neurologically impaired people
- to test the hypothesis that levels of social participation for a group of people with more severe dysarthria would be lower than those of people with less severe dysarthria
- to explore the accounts that speakers gave of changes to their social lives.

1.4 The importance of the research

The project was conceived as a method of evaluating the value of particular measures of social particiaption for use in assessment of motor speech disorders and was intended to have benefit for clinical practice. The contribution of the thesis is fourfold:

- scientific, in its findings regarding motor speech impairment and social participation;
- clinical, in identifying assessment tools which can broaden understanding of the impact of dysarthria on social lives;
- methodological, in showing the importance of using both quantitative and qualitative data to understand psychosocial sequelae of communication impairment;
- theoretical, in showing how communication disorder can be understood within a new domain: social capital.

1.5 Structure of the thesis: outline of each chapter

The purpose and content of each chapter is summarised below.

Chapter 2 Literature Review

This chapter presents the strategy for searching the literature. The results of that search are evaluated leading to the identification of the specific research topic, research questions and methodology. The neuropathology of Parkinson's disease is outlined and also the speech impairments which are associated with the condition. Intelligibility as a measure of severity in motor speech disorders is

discussed and the psychosocial consequences of speech impairment in Parkinson's disease are considered from the point of view of the speaker's perception of that experience. In the conclusion of this chapter specific hypotheses are proposed and justified.

Chapter 3 and 4 Quantitative Methodology

In this chapter the rationale for the research design is presented. Details are provided of procedures for participant recruitment and selection and the characteristics of the sample, processes for gaining ethical approval and steps taken to ensure that the study met ethical standards. Measures used are described and their validity and reliability presented in three categories:

1. non-speech measures which were used to control possible confounding variables;
2. motor speech measures, which were used to identify more and less severely speech-impaired participants;
3. social participatory measures, which were the dependent variables for this investigation.

These chapters contain the procedures for data collection including equipment used for recording and software for analysis of data, statistical processes, by which it was ensured that possible confounding variables of age, gender, socioeconomic status and education were controlled for in each of the

experimental hypotheses and the process of allocating participants to different groups.

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Chapter 5 Quantitative Results

In this chapter descriptive statistics and the results of statistical tests of the dependent variables for each of the hypotheses are presented.

Chapter 6 and 7

These chapters respectively present the approach to and methods of qualitative data collection and analysis (chapter 6) and the results of the thematic analysis (chapter 7)

Chapter 8 Discussion

This chapter integrates the quantitative and qualitative findings and explores the research topic and findings in detail, considering the scientific, clinical, methodological and theoretical contribution that is made. The results are related to the communication disorder literature. There is an exploration of the value of combined quantitative and qualitative research methods when investigating social participation. Finally, the application of alternative domains of knowledge to understanding of social participation in the context of communication impairment is considered.

The process of research is then assessed. This includes an evaluation of the methods used and suggestions for improvement. Ideas for extending the

research in the future and arrangements for dissemination of the findings are presented.

2 Chapter 2 Literature Review

2.1 Introduction

The literature review begins by providing a brief introduction to the neuropathology and characteristics of Parkinson's disease (hereafter PD) and to dysarthria. Following this the effects of PD on speech are outlined. There is an extensive literature on speech production impairment in PD but it is outside the scope of this project to review this field comprehensively. The literature review will then consider intelligibility which has been accepted by many authors as an index of severity of motor speech disorders (e.g. Kent, Weismer, Kent, & Rosenbek, 1989; Duffy, 2005), and will address issues relating to assessment of dysarthria.

As the primary aim of this project was to explore relationships between speech and social participation in PD, the second section will review the literature relating to social participation of the person with PD and how this is assessed. In order to explore what is understood about the effects of motor speech disorder on the social lives of those with PD, research into its impact on communicative and social activity and participation is reviewed. Concepts of social participation, communicative participation and communicative effectiveness are contrasted. Finally the research questions are stated which arise from areas so far undescribed by the literature.

2.2 Search Strategy

The following databases were searched for the period 1965 up to December 2012: Academic Search Premier, Cinahl Plus, Science Direct, Medline. Abstracts were searched for the term 'Parkinson's' and separately 'dysarthria' in combination with each of the following: activity, participation, social network, social life, intelligibility, conversation, discourse, interaction. Abstracts from the resulting hits were then scrutinised for relevance to the study. Reference lists of key papers were studied for additional items not retrieved through the database searches and a hand search of key journals was carried out from January 2013 forwards to the time of submission of the thesis.

2.3 Neuropathology of Parkinson's disease

PD is a progressive and degenerative neurological disease. In the majority of cases the cause of the disorder is unknown and is labelled idiopathic PD which accounts for 75-80% of cases (Gibb, 1992). Approximately 25% of patients who display the symptoms of PD do not have idiopathic PD and these patients are described as being parkinsonian. They may have PD symptoms as part of a syndrome such as Shy-Drager syndrome, corticobasal degeneration, Alzheimer's disease, Pick's disease or diffuse Lewy body disease (Troster and Fields, 2008). In such cases the condition may be referred to as a 'Parkinson's plus' syndrome as additional neuromotor symptoms are present. The symptoms of PD can also result from exposure to toxins such as carbon monoxide, as side effects of a range of medications, and appear as secondary to damage caused by encephalitis and traumatic brain injury (Nutt, Hammerstad, & Gancher,

1992). This study excluded participants with either Parkinson's plus syndrome or secondary Parkinsonism.

Idiopathic PD is associated with loss of dopaminergic neurones in the substantia nigra (pars compacta), with formation of Lewy bodies in the remaining cells and, in some patients, damage to the globus pallidus and corpus striatum (Troster and Fields, 2008). There is an incidence of 12-20 per 100,000 for developed countries which have a northern European age structure (Twelves, Perkins, & Counsell, 2003). The reported prevalence is up to 243 per 100,000 giving an average course from onset to death of 12-20 years (Hague et al., 2005). Idiopathic PD is therefore a relatively common neurological disease.

The loss of dopaminergic neurones results in motor impairment through involvement of a complex circuitry. The substantia nigra is anatomically and functionally closely related to the basal ganglia which include the caudate nucleus, putamen and globus pallidus. The basal ganglia form part of a control circuit for motor activity which together with the cerebellar control circuit coordinates and integrates voluntary actions with information about posture, spatial location, tone and functional goals. The basal ganglia have reciprocal connections with the cortex modulated by a direct route and an indirect route. In Parkinson's disease, loss of dopaminergic cells in the substantia nigra pars compacta results in disruption to both of these routes with a net increase in excitatory drive in the main output nuclei of the basal ganglia (globus pallidus internal and substantia nigra pars reticulata) which in turn leads to excessive

inhibition of thalamocortical motor output. This inhibition gives rise to the characteristic motor effects seen in patients. Cardinal motor signs originating from dopaminergic lesions are slowness of movements (bradykinesia), rigidity and resting tremor with difficulty initiating movements (akinesia) being common. Micrographia and reduced facial expression are sequences of these impairments which bear on communication but it is disturbance to the movements of the speech articulators which have the greatest impact on verbal communication (Schapira, Hartmann, & Agid, 2009).

People with PD often experience a range of other symptoms including mood disorder. It is well understood that depression commonly occurs in Parkinson's disease; for a review of the features and diagnostic criteria see Rickards, (2005). There is a great deal of literature available which examines the biomedical aspects of depression in PD but there is much less extant literature on the social experience of the person with PD although the two are likely inter-related. (Greene and Griffin, 1998) noted an association between PD symptom severity and marital quality suggesting that psychosocial status and medical condition may influence each other.

2.4 Motor speech disorder in PD

Disorders of speech which arise from impairments of the neural structures in the central or peripheral nervous systems for the control of speech movements are collectively known as the dysarthrias. As a group they are distinct from both disorders of verbal symbolic language (dysphasia) and also from disorders of motor planning (dyspraxia of speech). The critical distinction made is the

presence in dysarthria (and the absence in the other disorders) of abnormality in the strength, range or accuracy of the actions of the muscles which serve the speech system (Darley, Aronson, & Brown, 1975). Dysarthria refers to disorders affecting the quality of the speech sound signal where language expression is not involved (e.g. word retrieval, sentence formulation and semantic accuracy), although it is important to note that some recent work has proposed that conditions such as Parkinson's disease and ataxia give rise to motor programming as well as motor execution impairments (Kent, Kent, & Rosenbek, 1997; Spencer and Rogers, 2005). The term dysarthria is currently used to describe disorders of speech which arise from neuromotor impairments not only of the oral speech articulators (lips, tongue, velum and mandible) but also from disorders of respiratory and phonatory control which also affect speech intelligibility. The term typically excludes disorders that affect speech but which are structural in origin, such as post-glossectomy speech (Murdoch, 2009) where a section of the tongue has been surgically removed.

Since the pioneering work of Darley et al. (1975), classification of the dysarthrias has been strongly influenced by the hypothesised relationship of speech symptoms to impaired underlying neurology. In the case of PD, damage to the substantia nigra affects functioning of circuits in the basal ganglia giving rise to a pattern of dysarthria termed hypokinetic. Their perceptual speech symptoms in PD included rushes of speech, breathy and harsh phonatory quality, difficulty initiating speech, imprecise consonant production, monotone and low volume (Duffy, 2005). These symptoms can affect a variety of

structures within the speech production system (e.g. the lips, tongue, velum, larynx) and so individuals may present with varying profiles of speech impairment.

Clinical classification of dysarthria has long been based on perceptual appraisal of the speaker. Darley et al. (1975) classified the dysarthrias according to the speech characteristics which clustered for different pathophysiologies. A range of parameters (38) were rated using a 7 point scale to provide five dysarthria profiles which grouped for articulatory accuracy, pitch and volume control. Two studies using discriminant function analysis (Enderby, 1983) and (Chenery, 1998) obtained 89-90% accuracy in identifying dysarthric types. However, using speech characteristics to diagnose dysarthria type and possibly aid in identification of a lesion site is of less clinical relevance now than understanding which of the components of the speech system are most affected and have the greatest impact on communication. In any case, there are a number of areas of weakness in such descriptive approaches. The descriptions of speech are based entirely on perceptual rather than objective measures and these are subject to a range of biases and retest errors. Indeed Zyski and Weisiger (1987) found that clinicians were unable to make clinically useful diagnoses using perceptual assessment. There are also a number of studies which demonstrate poor correlation between perceptual and physiological measures of speech (Theodoros, Murdoch, & Thompson, 1995; (Theodoros, Murdoch, Stokes, & Chenery, 1993). Further, while it is possible to identify which components of the speech system are involved it is not transparent precisely what effect this has

on the speech signal itself. Finally, and in light of more recent developments in the approach to rehabilitation and healthcare most importantly, the functional and social impact of speech impairment on the speaker is not evaluated using this approach.

The relationship between the gross motor impairments which may present in PD and speech motor impairments is also not straightforward. As with limb movements, motor movement in the articulators for speech is characterised by hypotonic rigidity, reduction of movements, reduction in the speed of movement (bradykinesia) and tremor at rest (Duffy, 2005). However, there is some evidence to suggest that the control systems are not identical. In a PET study of Parkinsonian dysathria (Pinto et al., 2004) observed increased involvement of the premotor cortex and the prefrontal cortex which is different from the abnormal activations associated with hand motor tasks. Furthermore, the literature demonstrates that treatment that alleviates gross motor symptoms, such as use of levadopa, pallidotomy and deep brain stimulation, has varied effects on speech and intelligibility (Rousseaux et al., 2004; De Letter et al. 2005). Severity of dysphonia in PD is not correlated with the overall severity of the disease (Rosen, Kent, & Duffy, 2005) and there is no correlation between word intelligibility and overall severity of disease in either the ‘on’ or ‘off’ condition of medication in PD (De Letter et al., 2005).

A recent goal in research into speech in Parkinson’s disease has been to describe hypokinetic speech acoustically and physiologically. Earlier

descriptions, e.g. Darley et al., (1975) rest on perceptual impressions of speech. A more objective account using acoustic measures provides a more reliable way of characterising PD speech and potentially provides clinical advantages for assessment and management of speech impairments. The literature in this latter field has addressed the question of the acoustic signature of PD speech, the acoustic correlates of intelligibility and variation in speech which is either task-related or speaker-related.

2.4.1 Acoustic Signature

A methodological difficulty in studies of dysarthric speakers is that speech targets are often confined to very structured contexts such as fixed syllables, single words or carrier phrases rather than connected or spontaneous speech. There is some evidence to suggest that differences in speech between sampling tasks do occur in disordered as well as normal speakers (Brown and Docherty, 1995; Lowit-Leuschel and Docherty, 2001). There is limited literature relating specifically to PD although Kempler and van Lancker's (2002) finding that intelligibility in spontaneous speech is significantly lower than in structured tasks points to the clinical importance of clarifying this question. Spontaneous speech is typically elicited either by asking the speaker to talk on a familiar subject in a monologue or to engage in conversation with the researcher. Both of these are particular types of discourse genre distinct from naturally-occurring conversation and little is known about the effects they have on speech production. Contextual effects associated with the clinical or research setting have not yet been investigated and are not discussed by researchers with the

exception of Lowit-Leuschel and Docherty (2001) who found that as a group dysarthric speakers did not vary acoustic parameters between reading and conversation tasks but some individual speakers did. Therefore acoustic studies should be interpreted with a degree of caution in terms of how individual speakers may behave under different task conditions.

Acoustic accounts can verify or challenge the accuracy of accepted perceptual descriptions of impaired speech. A commonly reported perceptual feature of PD speech is increased rate (Enderby, 1983; Darley et al., 1975) but a number of studies have now compared PD speakers with control groups of normal speakers and found that articulation rate is not distinctive of PD speakers (Lowit et al.,2006; Ackermann and Ziegler, 1991; Ludlow et al., 1987). Articulatory imprecision is also not consistently supported by instrumental evidence. McAuliffe, Ward & Murdoch (2006) used electropalatography to record directly the extent of tongue-palate contacts during closure and demonstrated that the perception of articulatory undershoot was not supported by evidence of actual tongue position.

Perceptual characteristics of PD speech which do have consistent support from acoustic investigations include monotone/reduced pitch variation and decreased volume/intensity (Dromey, Kumar, Lang, & Lozano, 2000; Harel, Cannizzaro, Cohen, Reilly, & Snyder, 2004; Holmes, Oates, Phyland, & Hughes, 2000; Jones, 2009; Penner, Miller, Hertrich, Ackermann, & Schumm, 2001; Rosen, Kent, Delaney, & Duffy, 2006). Acoustic correlates of intelligibility in PD were

examined by Yunusova, Weismer, Kent, & Rusche (2005) and Weismer et al. (2001). In both studies reduced second vowel formant slope was associated with reduced intelligibility but it was not possible to isolate this measure as a component of intelligibility rather than simply an index of motor impairment severity. Yunusova et al. (2005) were able to isolate a prosodic measure, breath group length, as a significant predictor of intelligibility variation, in a study of speakers with motor neurone disease and PD.

The acoustic signature of PD, therefore, has not yet been clearly established due to methodological variations in studies including inconsistency in the use of control groups, inclusion of different types of dysarthric speaker within the same study and wide inter-speaker variation. It is possible that the potential of PD to affect a wide range of speech output structures at different times means that speech impairments in PD are more heterogeneous. Further research is required to establish whether sub-groups of impaired speakers exist.

In summary, although this literature is extensive it has a significant limitation from a rehabilitation perspective in that it focuses on description of the speech impairment and does not attempt to link this to the way that dysarthric speakers convey meaning and achieve social goals through communication in everyday situations. It can be argued that studies which focus on factors which contribute to intelligibility rather than aspects of the speech signal alone do address meaning and communicative success as speaker intelligibility is central to

achieving successful communication. For this reason, intelligibility in PD has been considered in detail below.

2.5 Intelligibility

Speech and language therapists are rightly concerned with attempts to understand the communicative ability of people with impairments such as dysarthria. Intelligibility is a central construct in such an understanding and has been described as 'the most clinically and socially important aspect of [the dysarthrias]' (Ansel and Kent 1992, p297). Recently, it has been suggested that it may be an important marker of the progression of cognitive-linguistic communication impairments in chronic disease such as multiple sclerosis (Mackenzie and Green, 2009). Intelligibility has been usefully defined as the extent to which a speaker's intended message is recovered by the listener (Kent et al. 1989) and the accuracy with which a message is conveyed (Yorkston and Beukelman, 1980). Beukelman and Yorkston, (1979) suggested that the strong relationship between intelligibility and information transfer also marks it as a useful index of communication performance. These are essentially functional definitions; they focus on intelligibility in relation to the outcome of a communicative interaction at the level of the message, i.e. how much of the intended message was transferred to the recipient, (Kent and Kim, 2011) as distinct from the quality of the speech signal or perceived degree of distortion in the speech. This is important because although intelligibility was once regarded as a speaker attribute, a consequence of the degradation of the speech signal, it can now be recognised that intelligibility is a relative quantity which is context-,

not speaker-, dependent. The ability of a speaker to produce speech sounds accurately is not the defining parameter of intelligibility but is only one parameter among many. Others include the type of material used to assess intelligibility (e.g. reading of single words or sentences or spontaneous utterances), the conditions in which the assessment occurs (audio, video or live speech), the behaviour of the listener and the environmental interference. Thus it is not possible to state that an individual has an intelligibility of X without also specifying the state of all of these variables.

There is increasing recognition of the contribution to intelligibility of factors which are not part of the speech signal per se. For example Garcia and Dagenais (1998) demonstrated that semantic predictiveness of utterances and use of iconic gesture enhanced intelligibility in a group of dysarthric speakers. (Hustad, Jones, et al. 2003) and Hustad, Auker et al. (2003) reported benefits to intelligibility through the introduction of topic and alphabet cueing by the dysarthric speaker. These findings demonstrate the importance of the listener's linguistic-contextual knowledge of the intended utterance when measuring intelligibility. Listener familiarisation with the speaker also increases listener comprehension of target sentences (Hustad and Cahill, 2003). There is thus growing evidence showing the importance of a range of contextual variables on intelligibility. It would seem logical to assume that loss of intelligibility would have a negative impact on communication in social settings and that awareness of this might influence decisions that speakers take about when and how they engage socially. However, the relationship between intelligibility and

communication in social situations is complex will be explored in greater detail below.

It is still not settled what kind of task provides material for best evaluation of intelligibility. Various methods have been devised for measuring the extent to which dysarthric speakers can be understood by listeners but there is no single measure flexible enough to capture all information relevant to speakers, listeners, communicative task and environment. Methods which make use of scaling techniques to arrive at a global judgement of intelligibility without reference to content of the message are not well-suited to multi-dimensional measures such as intelligibility (Kent and Kim, 2011) and there is evidence that listeners using such measures do not distinguish between intelligibility and severity of speech distortion (Whitehill, Ciocca, & Yiu, 2004). Furthermore, comparison of results between studies using scaling measures is problematic without standard referents (Weismer and Laures, 2002). Methods which focus on message content such as word identification, sentence and conversation transcription require care in controlling utterances and do not distinguish between information that is recovered at the acoustic, linguistic and semantic levels (Sussman and Tjaden, 2012). Indeed, transcribed intelligibility scores do not correlate strongly with listener comprehension (Hustad, 2008) which might be expected to be of central importance in a measure of intelligibility. These issues are explored here and also within section 4.2.2 in the method where the decision-making regarding choice of speech measures for this study is set out.

2.5.1 Intelligibility in Parkinson's Disease

Studies which have investigated intelligibility in PD have explored a number of issues which are relevant to the understanding of intelligibility in dysarthria in general. These include specifying acoustic and speech correlates of intelligibility, the effects of different tasks for gathering data and the impact of non-speech variables on intelligibility. There is considerable methodological variation in the published literature which can make comparison of results difficult. For example, Kempler and Van Lancker (2002) and Neel (2009) draw different conclusions on the effect of loudness on intelligibility. However, Kempler and Van Lancker conducted a single case study with word, sentence and conversation tasks, which arguably offer more ecologically valid utterances, whereas Neel conducted a group study with better evidence of listener reliability but without using a conversation task. Differences are to some extent dictated by the particular aims of the study. For example, Adams et al (2008) focused on the effect of background noise as it affected speaker output with a group of 25 PD speakers using only 2 listeners to evaluate intelligibility. In contrast, Kempler and van Lancker, (2002) investigated a number of different presentations of the same spoken material (reading, repetition, singing) taken from a single speaker with PD but making use of 64 listeners. This reflects a central issue; both listener and speaker play a key role in message understanding. Hence studies of intelligibility may be directed at either listener or speaker or both, and studies which have the potential to contribute the most will recruit in numbers from both groups. Only one study (Miller et al., 2007) recruited both a large sample of PD speakers (n = 125) and listeners (n = 99).

Listener familiarity with dysarthric speech may positively affect intelligibility ratings (De Paul and Kent, 2000). Familiarity of the listeners with dysarthric speech is commonly reported (Bunton et al., 2001; Bunton and Keintz, 2008; Keintz et al., 2007; Miller et al., 2007; Neel, 2009; Tjaden and Wilding, 2011; Walshe et al., 2008; Weismer et al., 2001; Yunusova et al., 2005). However, the impact of previous experience on intelligibility rating of dysarthric speech is variable.

PD is frequently well-controlled by medication and therefore the timing of assessments relative to the medication cycle is important. Fluctuations in effect are part of planned medication cycles but 'off' periods may also occur unpredictably. Approaches to manage this include employing standard practically-defined 'off' and 'on' periods, or asking patients to identify an optimum time in their medication cycle (Bunton and Keintz, 2008; Adams et al. 2008; Beverly et al. 2010; De Letter et al. 2005; Defer et al. 2003, Hammen et al. 1994, Miller et al. 2007, Plowman-Prine et al., 2009; Ramig, 1992; Tjaden and Wilding 2011; Nakano et al., 1973; and De Letter et al., 2005) report improvements in intelligibility during L-DOPA administration although numerous studies indicate that the effects on specific aspects of speech and oral function are inconsistent (Critchley, 1981; M De-Letter et al., 2006; Miet De-Letter et al., 2007; Louis, 2001; Sanabria, Ruiz, Gutierrez, & Marquez, 2001)The effects of sub-thalamic nucleus (STN) stimulation on speech intelligibility have been studied using a transcription based assessment (Rousseaux et al., 2004) but STN had only a weak effect on speech and no effect on intelligibility measures.

Speaker adaptation of speech can also affect intelligibility. Studying both ataxic and hypokinetic dysarthric speakers Yorkston et al. (1990) found that sentence intelligibility increased as speaking rate decreased. For a control group, the same reductions in rate also resulted in significant judgements of decreasing naturalness. This was not the case for the dysarthric speakers because, the authors surmised, their speech was already perceived to be distorted.

A range of tasks have been employed to control for confounding variables but with accompanying loss of some face value. Reading of words, sentences and passages allows a degree of standardisation but at the cost of ecological validity. Conversation and spontaneous monologues may be closer to a speaker's functional intelligibility and conversational utterances have greatest face value but are harder to control. In studies relating to Parkinson's disease a range of tasks has been used (see table 1). It can be seen that only two studies of eighteen, De Letter et al. (2005) and Nakano et al. (1973) did not use some measure of connected speech (i.e. restricted assessment to single words). However, only seven employed tasks which involved spontaneous production of connected speech, either as a monologue or in conversation. Scaling and item identification techniques have been used in investigations of speech in PD and there is evidence that they may assess different aspects of intelligibility. Investigating within-speaker variation in intelligibility, Yunusova et al. (2005) compared direct magnitude estimation (DME) (without modulus)[1] with

[1] [1] In modulus free DME listeners rate the speech they hear against a working definition of intelligibility, e.g. 'the ease with which speech is understood' (Bunton et al 2001). In DME with

transcription of sentences and found that a prosodic dimension (distance between breaths) predicted within-speaker variation while a segmental acoustic

Table 2-1 Speaking tasks in studies of intelligibility

	Speaking task				
Study	**Word**	**Sent.**	**Pass.**	**Mon.**	**Conv.**
Adams et al (2008)					+
Bunton et al (2001)		+			
Bunton and Keintz (2008)	+	+		+	+
Beverly et al (2010)		+			
De Letter et al (2005)	+				
Hammen and Yorkston (1994)	+	+	+		
Keintz et al 2007)		+			
*Kempler and Van Lancker (2002)**		+			+
Miller et al (2007)				+	
Nakano et al (1973)	+				
Neel (2009)		+			
Plowman-Prime et al (2009)	+		+		
Ramig (1992)					+
Rousseau et al (2004)					+
Tjaden and wilding (2011)			+	+	
Walshe et al (2008)		+	+		
Weismer et al (2001)	+	+			
Yunusova et al (2005)	+		+		

Word = single word reading,
Sent. = sentence reading,
Pass. = reading passage,
Mon.= spontaneous monologue,
Conv. = spontaneous conversation
**also tested repetition and singing of text*

dimension (f2 slope) predicted inter-speaker variation using DME but not using transcription, although the authors acknowledged that the latter was a relatively coarse measure. Indeed, Bunton et al. (2001) evaluated the effects of flattened

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modulus listeners are first given a sample of moderately-dysarthric speech and then asked to rate the target speech samples against this standard

fundamental frequency (f_0) (a prosodic dimension of speech) on intelligibility in speakers with PD and found that variations in f_0 had a significant effect on ratings of intelligibility using both transcription and DME. There may be evidence, therefore, to suggest that DME and transcription scores are reporting on different aspects of intelligibility although both may index the severity of the underlying impairment to a significant extent. This is to be expected in that transcription based assessments compare intelligibility with 100% listener recovery of the words spoken, while in natural conversation it is sufficient for listeners to extract only the information needed to meet the communicative and social goals of the utterance. Differences in these measures may differentially affect intelligibility ratings of different dysarthria types. (Weismer et al., 2001) found that scaled intelligibility using DME with modulus resulted in lower intelligibility scores for a PD group compared to a group with ALS (amyotrophic lateral sclerosis) whereas single word transcription did not distinguish the two groups. It is possible that prosodic rather than segmental differences between the two groups underlie these findings. Indeed, Weismer et al's investigations of vowel characteristics in the PD speakers found no difference to a control group. Similar findings were made by Sussman and Tjaden (2012). Speakers with PD, multiple sclerosis and a control group were undifferentiated by transcribed intelligibility scores but judgements of severity of speech distortion were sensitive to the presence of the underlying speech impairments.

These findings may help to explain lack of correspondence between dysarthria severity as measured by intelligibility and psychosocial impact. It is to be

expected that dysarthric speakers will be aware of underlying impairment even where transcribed intelligibility is at a normal level (Walshe et al., 2008) and this may affect interaction in social settings. However, nor can it be assumed that scaled judgements of intelligibility match speakers' evaluations of their speech. Measures which take account of the underlying speech impairment may therefore also be necessary when evaluating the impact of dysarthria on speakers' social communication.

Non-speech factors may also affect intelligibility. Cognitive functioning is impaired in a substantial number of people with PD and might be expected to adversely impact speaking tasks, especially where the participant is expected to extemporise. Cognitive screening is therefore commonly reported (Adams et al., 2008; Bunton and Keintz, 2008; Miller et al., 2007; Plowman-Prine et al., 2009; Rousseaux et al., 2004; Tjaden and Wilding, 2011; Walshe et al., 2008). Other non-speech factors have been investigated. In day-to-day communication speakers are required to carry out other tasks simultaneous to speaking which divide their attention. This may be achieved easily in an unimpaired population but PD speakers carrying out a simple motor task while producing speech were significantly less intelligible in a range of tasks (Bunton and Keintz, 2008). The authors hypothesised that this lower level of intelligibility was closer to that achieved in typical functional conditions. Environmental conditions are also relevant. Where speech is distorted, as in dysarthria, a listener will be more affected by levels of background noise. Adams et al. (2008) found a statistically powerful effect of speech to noise ratio on intelligibility in a group of PD

speakers compared to an unimpaired control group in conversational speech. This demonstrates the importance of communication context when measuring intelligibility. Where the listener is unable to see the speaker's face the lack of non-verbal cues and phoneme-specific visual information such as lip position may affect intelligibility (Keintz et al., 2007).

Other non-speech factors to consider are the effects of PD treatments including medication and deep-brain stimulation.

In conclusion, when considering the discourse of dysarthric speakers, it should be remembered that measures of intelligibility, whether percentage of accurately transcribed words or listener ratings of adequacy, are global indicators which may index the overall severity of the speech impairment but do not inform us about the way in which speakers express meaning or how they engage in conversational or other communicative interaction. There is thus a limited understanding from the existing research of how intelligibility contributes to communication in social situations and supports people with dysarthria in maintaining social activity or social networks and, conversely, how reduction in intelligibility impacts on participation. Studies which have explored constructs related to participation have not found a linear relationship between measures of intelligibility and speaker perceptions of their communicative ability. (Donovan et al., 2008; Hartelius et al., 2008; Miller et al., 2011; Tjaden & Wilding, 2011)These studies will be reviewed in more detail below.

2.6 Communication in Social Interaction

In the previous section the speech characteristics of PD and the effect of PD on intelligibility were reviewed to provide an understanding of communicative impairment in PD and the effect on communicative activity. In the following section aspects of communication change relating to interaction are reviewed, the concept of social participation is examined and literature which has investigated social participation in PD and the effects of dysarthria on psychosocial functioning is reviewed.

A relevant goal for the study of any form of communication impairment is to understand how communication takes place in everyday situations and what impedes it; that is to say, how the impairment impacts on the discourse of the individual and on their ability to use communicative resources to complete communicative activities, interact with others, participate in communicative acts and social situations and ultimately fulfil social roles. The relationships between impairments, activities and participation are modelled in the ICF (WHO, 2001). Other factors may affect participation, including personal factors and environmental factors. The former include for example age, social background, education and response to the underlying condition and rehabilitation needs. The latter include for example attitudes, relationships and support from others and services. In speakers with PD some of the resources required for successful communication may be reduced and it may be inferred that this will impact on their ability to complete activities effectively and participate fully. This section will review literature relevant to this issue. Although the literature

relating to participation and dysarthria is not very extensive it is growing and researchers in this field have tackled various aspects of it. In doing so they have adopted a variety of conceptual approaches which are structural, functional and psychosocial and these will be discussed here.

Participation is now a central concern of rehabilitation as reflected in models of health and disability such as the ICF where the emphasis has moved from a focus on impairment to include impact on activity and participation. The WHO defines participation as 'involvement in life situations (WHO, 2002). How impairment impacts on participation has been investigated in a number of studies but a difficulty that arises is lack of agreement about how to define participation more narrowly and how to measure it (Yorkston, Bamer et al., 2012). A number of published measures exist which all derive their items from domains of the ICF and have construct validity but vary widely in terms of which domains are used (Magasi and Post, 2010) and it is acknowledged by these authors in their review of the literature that there is no accepted criterion for measuring participation. There is therefore a lack of precision about what participation means from the point of view of clinicians and researchers. People with disabilities also do not describe participation as having a standard criterion but characterise it as complex and multidimensional, having both structure and process. In accounts of participation by people with disabilities, social activity and connections formed part of concepts of participation but having control of access and opportunity and taking responsibility for social involvement are also

important, participation being characterised as dynamic and reciprocal (Hammel et al., 2008).

In the absence of an agreed measure for participation researchers in the field of communication impairment have operationalized participation in a number of ways (Dalemans, De Witte, Wade, & Wim, 2007). Studies of people with aphasia which have adopted quantitative measures of activity have found for example effects of aphasia severity on hours spent outside the home (Code, 2003), conversational experiences (Ross, Winslow, & Marchant, 2006), loss of friends from the social network (Northcott and Hilari, 2011, Hilari and Northcott, 2006) and reductions in activity and network size (Cruice, Worrall, & Hickson, 2006). Other aspects of participation quantified in aphasia research include domestic, education and employment activity (Dalemans et al., 2007). None of these measures captures in detail the subjective value of the items quantified such as the nature of the relationships or the importance of the activities to the speaker. Nevertheless these quantitative measures appear to be sensitive to the degree of communication impairment. Like other people with disabilities, people with aphasia do not describe type or quality of activity as most important regarding participation (Dalemans, de Witte, Wade, & van den Heuvel, 2010). Similar results have been obtained for stroke-related dysarthria (Brady, Clark, Dickson, Paton, & Barbour, 2011). Participants interviewed by Brady et al. described disrupted interactions, specific situational difficulties, avoidance of social situations and speaking opportunities, changes to sense of self and barriers to participation caused by the behaviour of others. In this study the

extent of any co-existing aphasia was not detailed and so the specific impact of dysarthria is not entirely clear but findings from a group of speakers with dysarthria and PD (Miller et al., 2006) indicate that dysarthria does have a negative impact on how people perceive themselves as competent communicators, on quality of their interactions and on inclusion in social experiences. In this study also, the behaviour of listeners was influential on shaping decisions to avoid social situations and contact with others. It is evident then that quantitative aspects of social participation may be sensitive to communication impairment but social participation in its entirety involves other factors such as how interactions take place, speaker and listener behaviour, changes to patterns of behaviour which may include gains as well as losses and feelings towards communicating in social situations.

The complexity of social participation renders assessment difficult, a key issue being the purpose of assessment. In order to provide effective intervention to the individual the individual's perspective must be understood. Walshe et al., (2009) addressed this issue with the development of the Dysarthria Impact Profile (DIP). The five domains of the DIP are conceptually related to aspects of participation highlighted as important to communication impaired speakers: effect of dysarthria on the self-concept; acceptance of dysarthria; perceptions of others' reactions to speech; how dysarthria affects communication with others; dysarthria relative to other areas of concern. The DIP accords with Magasi and Post's (2010) recommendation that participation measures align with users' concept of participation as well as researcher interests. The profile includes

items which rate change and restrictions to social life and which therefore scale perception of the social consequences of dysarthria although, as the authors acknowledge, the DIP 'does not assess participation per se' (Walshe et al., 2009, p695).

A concept closely related to social participation is that of communicative participation. While social participation is defined as involvement in life situations, Eadie et al. (2006) in a review of measures of communicative participation defined the latter as 'taking part in life situations where knowledge, information, ideas or feelings are exchanged' (p309). Communicative participation encompasses that range of interactions where communication is required. According to this definition communicative participation can therefore only take place where another individual is present. There is thus a fine distinction between life participation and communicative participation. Although communication is a significant component in very many life situations, when participation is considered as an end goal it is not necessarily implied that communication exchange as defined by Eadie et al. is taking place. Communication is a valuable but not the only means by which we achieve social action (Simmons-Mackie and Damico, 2007). For example, reading and listening to the radio may contribute to fulfilment of, and therefore participation in, life roles but do not qualify as communicative participation because there is no exchange of knowledge, information or feelings between individuals. Communicative participation has been measured using self-ratings of the impact of multiple sclerosis on a range of communicative situations (Eadie et

al., 2006) and is negatively associated with dysarthria but also with fatigue, mood and social support. This points again to the complexity of participation as a concept.

2.6.1 Effect of dysarthria on interaction

In this section will be considered what is known about the way that dysarthria impacts on aspects of communication which might be expected to contribute to successful participation and to which qualitative reports refer: speech sound distortion, lexical and syntactic impairments and pragmatic deficits. After this, conversational analytic findings will be considered as management of interaction is central to the construction of social relations.

Of those studies which examine speech production in discourse of people with dysarthria there is a relative dearth when compared to the studies which investigate dysarthria within more highly constrained contexts such as single syllables, single words and reading aloud of sentences and paragraphs. Studies which are limited to discourse within PD are few (Bunton & Keintz 2008; Rosen et al., 2006; Rosen et al., 2005; Harel et al., 2004; Bunton, 2005; Goberman & Elmer, 2005) and such studies as exist present a range of discourse types. These are often referred to as 'spontaneous speech' although this is a questionable label as they may include clinic or laboratory-based conversations (Kempler & van Lancker 2002), exchanges prompted by standard questions (Rosen et al., 2006, 2005) and monologues prompted by a single question or direction (Bunton, 2005). The usefulness of the findings in contributing to understanding the relationship between dysarthria and participation is limited as

the aims of the studies were typically unrelated to such goals but do identify stable acoustic and physiological correlates of intelligibility and dysarthria in PD . How easily these findings can be generalised to naturally-occurring social communication is not yet clear and such examinations of discourse tell us very little about how that discourse is used to achieve social and communicative goals.

In relation to linguistic structure, issues that should be addressed include the impact of Parkinson's disease on production of language (and so its impact on the formulation of meaning) and the extent to which this impacts on the interaction between speaker and listener. Little is known so far about linguistic form in the discourse of speakers with PD and from these findings it is not possible to conclude that lexical and syntactic variation in PD affects discourse. Historically, the emphasis in research has been on the changes to speech production rather than language, as detailed above. A limitation of studies which have addressed lexis and syntax in PD is that theoretical orientation to language structure is not made explicit and therefore comparability of findings is harder to assess. Illes et al. (1988) investigated PD language in a spontaneous speaking task in comparison with matched controls and noted that PD speakers produced fewer modalisations[2], less complex syntax, more open class phrases[3] and more pauses. Iles et al interpreted these findings not as a primary deficit in sentence planning and formulation but as a strategy which was used to reduce

[2] Expressions by the speaker which qualify the content of the message e.g. 'you know', 'I guess'.

[3] Open class phrases employ content words e.g. 'I went *to Chicago*', closed class phrases employ function words e.g. 'That's *about it*' (Iles et al, 1988 p152).

unnecessary language and maximise the utility of each utterance. Murray & Lenz (2001), also concluded that syntactic deficits were not a primary symptom in PD. They found no significant differences between PD speakers and controls on a range of syntactic variables including proportion of closed class words, complex sentences, embeddings and verb inflections. In contrast with Iles et al. (1988) these findings do not suggest a strategy of discourse alteration in order to economise on effort. Murray and Lenz did find that level of cognitive deficit was positively related to syntactic accuracy and argue that syntactic deficits in PD may therefore be limited to cognitive demand.

A number of researchers have investigated discourse in PD from the perspective of how interaction is organised and managed. In such investigations, the syntactic content of utterances is of less importance than the ability to use conversational turns to achieve communicative goals. In some cases a more theoretically-constrained framework has been adopted with the application of speech act theory, Gricean maxims (Holtgraves and McNamara 2010b) and politeness theory (Holtgraves and McNamara 2010a). Here it is helpful to be directed to a consideration of the differences between direct and indirect meaning and how difficulties with understanding indirect meanings may cause problems for interactions. However, the limitations of speech act theory in determining a comprehensive set of speech act types that can be mapped onto individual utterances should be born in mind when considering naturally-occurring speech rather than idealised dialogue (Lesser and Milroy, 1993). Other researchers have adopted what might be termed a functional approach

which is concerned with how speakers are able to manage conversations. This is expressed in a variety of ways such as how effective they are or perceive themselves to be in a variety of communicative situations (Donovan et al. 2008) and how successful they are in accomplishing daily tasks and using language in the real world (McNamara & Durso, 2003). Related to this is the use of 'appropriacy' as an external judgement of the relevance of an utterance to a communicative exchange (McNamara & Durso, 2003). A functional approach also takes interest in the way that speakers manage turn-taking and topic across the conversation and in relation to its social context (Whitworth, Lesser, & McKeith, 1999).

Primary pragmatic deficit

In relation to the ability of speakers with PD to use language in social situations one line of enquiry currently being pursued concerns the hypothesis that there is a primary pragmatic deficit associated with PD. This proposes that the neurological degeneration not only affects the systems for motor control of speech (with secondary effects on ability to manage interaction) but also the ability to understand social situations and act communicatively in ways that are relevant, timely and non-problematic for interlocutors. Speakers with PD not only score lower than controls on assessments of pragmatic ability (McNamara and Durso, 2003; McKinlay et al., 2009) but also show less insight into their ability, overestimating themselves when self-rating on the same scale compared to spouse/partner ratings (McNamara and Durso, 2003), a finding which is

repeated in other studies of communicative effectiveness (Donovan, 2005; Donovan et al., 2008). It is hypothesised that what underlies this is degeneration of fronto-striatal circuits. Reduced ability to vary politeness formulations according to situational need was reported by Holtgraves & McNamara (2010b). The same authors investigated ability to recognise implicit speech acts and found that PD participants were less aware of the speech act content of utterances and less able to label speech acts accurately although they were just as confident in the accuracy of their judgements as control participants were. These studies indicate that in some PD participants there is a primary deficit of pragmatic ability although the expression of such a deficit in naturally occurring communication has not been explored as yet. Diminished awareness of pragmatic ability is also present and both aspects of the deficit appear to be associated with decline in aspects of frontal lobe functioning. This is part of a complex picture in which awareness of global pragmatic functioning may be differentially affected compared to awareness of communication relating to specific communicative contexts. In contrast to the above findings Miller et al. (2008) found that speakers with PD rated their communication as more negatively affected by PD than carers did and this may play a role in undermining confidence about social interactions and help to explain the lack of relation between intelligibility and psychosocial consequences.

Although there is an absence of a unifying theoretical stance toward analysis of conversation within the literature relating to discourse in PD, researchers share a concern for similar areas of interactions including initiation of conversation,

turn-taking, repair and topic (Kegl and Poizner, 1998; McNamara and Durso, 2003; Whitworth et al,. 1999; Griffiths, Barnes, Britten, & Wilkinson, 2011; 2012). Kegl and Poizner's study was of 3 deaf-signers with PD rather than dysarthric speakers but the interactional analysis bears some comparison with conversation analysis (CA) studies of spoken discourse. For example, the authors describe conversation as a mutually negotiated operation which is consistent with the CA approach even though CA per se is not mentioned. A limitation of this study is that the data are not presented in the form of conversation transcription but rather instances of particular behaviours are tabulated. This presentational approach does not allow the reader to evaluate the contextual factors in play at any moment in the conversation. The authors note a decrease in the number of back channel responses in their moderately severe participant, which is also reported in speaking dyads by McNamara and Durso (2003) but temporal management of conversation (e.g. avoidance of overlap or pausing between turns) was maintained.

Other researchers have recorded features of conversation which are different in speakers with PD compared with controls. The pattern of breathing, length of breath group and duration of in-breath are different in PD speakers (Huber and Darling, 2011; Bunton, 2005). In addition, PD speakers make more formulation errors (signified by self-initiated repairs such as restarts) and produce fewer filled pauses. Unimpaired speakers in the same study used more short breath groups with content-free fillers. These findings suggest that speakers with PD are more likely to employ a floor-holding strategy which depends on maintaining

a typically longer stretch of speech between breaths and greater use of content vs. filler words in short breath-groups. This is likely to be a response to limitations on coordination of speech with respiratory support. However, the relative lack of sentence planning opportunities that this strategy affords the PD speakers (evidenced by the fewer filled pauses) may result in more formulation errors. Miller (2009) also comments on the increased likelihood of attributable pauses in PD speech caused by hesitations in speech and sentence formulation problems. These pauses make it more likely that the speaker will lose the floor, a view which is supported by the experience of speakers themselves (Miller et al., 2006).

The relative contribution of the impaired speaker to conversations is a recurrent theme in this literature. Conversational initiation was found to be reduced both in analysis of conversational data (Whitworth et al., 1999) and perceptual reports of others (McNamara & Durso, 2003). Whitworth et al. (1999) also found that speakers with PD initiated less often, were less able to maintain topics and to respond when offered a conversational turn. It must be taken into account that the investigation focused specifically on speakers who also had cognitive impairments and so findings cannot be attributed solely to motor speech limitations. However, in light of the findings of Holtgrave and McNamara (2010a, 2010b) and McNamara and Durso (2003) it cannot be assumed that pragmatic ability is intact even where people are at a relatively early stage of the disease.

Reduced contribution to interaction was also found in self-reports by Miller et al. (2006), Miller et al. (2008) and Walshe and Miller (2011) where speakers report greater passivity, passing more of the burden of communication on to carers and letting others talk for them. In a review of interactional competency in Parkinson's disease Griffiths et al. (2011) assert that the consequences of speech impairments are very wide, up to and including 'complete social withdrawal' (p498) although the nature of that withdrawal is not specified. Miller et al. (2006) highlights the role that self-perception plays in relation to this as speakers report both difficulties associated with word retrieval and sentence formulation and also the apprehension towards interaction that inhibits contributions. It would appear that how speakers perceive themselves in communication may be as significant a factor affecting conversational performance as objective impairments such as speech production or language processing. A further aspect of discourse that is affected in PD and other types of dysarthria is the content and purpose of conversational exchanges. Some speakers report that they engage in less small talk and tend to make exchanges briefer by leaving out less essential banter (Walshe and Miller, 2011).

Some initial work using conversation analysis (CA) has been carried out with dysarthric speakers of different aetiologies (Comrie et al., 2001; Bloch and Wilkinson, 2009; Bloch and Beeke, 2008; Bloch and Wilkinson, 2004) and of speakers with PD (Griffiths et al., 2012). The basic orientation of C.A. is summarised as follows (Atkinson and Heritage, 1984):

I. interaction is structurally organised
II. contributions to interaction are context-shaped and context-renewing
III. no contribution can be dismissed as disorderly or irrelevant
IV. the study of social interaction in its details is best approached through analysis of naturally occurring data

The method of CA is entirely lodged in data that are naturally occurring i.e. that would exist whether or not recording had taken place. Naturally occurring data is preferred because other forms of data are unsatisfactory from the point of view of authenticity of social action and the range of conversational structure they can demonstrate. It follows from these precepts that selection of conversational phenomena as categories for analysis a priori is inappropriate. The techniques used by Bloch and Wilkinson (2004) are consistent with this as no researchers were present during recordings and no conversation topics were predetermined. The authors highlight the management of repair in conversations with Alternative and Augmentative Communication (AAC) users as a means of demonstrating how participants in a conversation display and manage problems in understanding speakers' turns as it was apparent from the data that other-initiation of repair was a persistent phenomenon. They found that AAC was selectively used for self-repair of turns but that intelligible AAC contributions did not necessarily result in complete understanding, reinforcing the point that intelligibility and comprehensibility are not identical, an issue that could be explored more fully in relation to speech of different degrees of intelligibility. There is a strong argument for using this methodology which has been used to great effect in understanding the discourse of people with

aphasia. Griffiths et al. (2012) examined phenomena relating to overlap in the conversation of people with PD and reported that overlap and turn deletion resulted from PD related pausing behaviour. The degree of disruption to interaction was unrelated to intelligibility. There is a research need to carry out further examination of the conversation of dysarthric speakers with PD such that the nature of conversational contribution, conversational breakdown and repair can be understood more fully and phenomena associated with conversational participation and withdrawal delineated.

2.6.2 Social Participation and Communication in Parkinson's Disease

Recent literature has begun to describe the experience of Parkinson's disease from the patient's perspective and to analyse it from social as well as psychological viewpoints. This work is generally interview-based, qualitatively analysed within a phenomenological framework, and is generally small-scale with consequent limitations. Some common themes emerge from patients: concerns about capability, social competence and stigmatisation. For example, Sunvisson and Ekman (2001) reported that PD is experienced as enslavement and loss of control. There are particular gender implications within these constructs. Caap-Ahlgren (2002) in a study of Swedish women with PD found that loss of a stable body image and inability to maintain traditional female competences were key issues.

Considering communication pathology, a key finding is that in many cases the struggle to adapt to fluctuations in physical and social competence leads to social withdrawal (Elgrig et al, 1999 cited in Hodgson et al., 2004). A large

survey (Macht, Schwarz, & Ellgring, 2005) found that approximately 50% of people with PD experienced problems with social stress and for 12-13% there was a worsening of their marital relationship. Karlsen et al. (1998) surveyed quality of life and found that a PD group scored higher for social isolation than either a normal group or a matched diabetic group indicating that social withdrawal is intrinsic to PD rather than chronic disease in general. Other studies have also found evidence of diminished social functioning and quality of social relationships (Lee et al, 2006; Schestatsky et al., 2006). This is concerning as Frazier (2000) found that withdrawal from social support is associated with poorer physical and mental outcomes. It should be noted that patients are sensitive to the impact their disease can have on interaction with others even before there is any real loss of speech intelligibility (Miller et al., 2006) and so it is unsurprising that withdrawal from social situations would be a common compensatory strategy. It is possible that this may be reversed, however. Sunvisson and Ekman (2001) actively targeted social relationships in their intervention. PD patients spent one week in a mountain location where they were encouraged to participate in physical activity and engage in unstructured social contact with other patients and carers. At a three month follow up they reported renewed feelings of capability and improved social lives and for the authors this constituted a change in the phenomenological state of the participants. As a consequence of their living with PD, what the authors refer to as the participants 'being towards the world' had first been transformed into 'being towards the body' but as a result of the intervention this was returned to 'being towards the world'. In other words, PD had first led to an illness-

centred approach to life while therapy had subsequently re-established a normal, socially-oriented way of living. It is important that the benefits from the intervention came from planned but unstructured physical and social contact so the extent of this kind of activity in people with PD is a matter of importance and should be understood more fully.

Nijhof (1995) explains withdrawal from social relationships in relation to rules (or norms) governing social behaviour which people with PD are obliged to break because of the constraints of their condition. Such rules have common characteristics such as regulating everyday life, relating to behaviour as an adult and being internalised as behavioural norms. Examples given are the rule of being able to speak normally or the rule of being competent in a social situation. Thus, in breaking these rules, people with PD construe themselves as socially incompetent and experience PD not primarily as a cause of physical but of social disability leading to withdrawal from the public domain.

Some quantitative aspects of social functioning in groups of people with Parkinson's disease have been investigated in two studies of a reasonably large scale, one in the USA published in a series of papers (Singer, 1973; 1974a; 1974b; 1976) and one in the UK (Oxtoby, 1982). Singer recruited from hospital departments in six major US cities resulting in a sample that reflects urban rather than rural preoccupations. Oxtoby recruited from a self-help organisation resulting in a sample that is essentially self-selected. In both cases the participants responded to standardised questions either in a structured interview

or a questionnaire. The structured nature of the investigations placed limitations on the scope of the work to explore qualitatively concepts such as friendship and loneliness and so constructed social participation simply in terms of recordable events such as visits to and from family members and membership of organised social groups. The samples used in both studies were not representative of the general population of a similar age in having a higher educational level, in the US study over-representing some religious groups and in the case of the UK study over-representing non-manual professions. Comparisons were made for some measures using data taken from a range of sources such as population census. Singer used inferential methods to address her research questions which involved patterns of change over a nine-month period following the start of treatment with levdopa. Oxtoby presented descriptive data from a single point in time only with no inferential testing. In specific areas of functioning the questions were sometimes relatively crude and communicative functioning was not investigated in depth.. For example speech function was measured using a three point scale: 'no difficulty – strangers often have some difficulty understanding what I say – strangers never understand me' (Oxtoby, 1982). While the aims of Singer's and Oxtoby's work were different, together they provide the little information that is available on the social functioning of PD patients considered as a group. The findings can be summarised thus: the presence of primary PD is associated with deterioration in activity and social functioning which is marked by lowered likelihood of fulfilling certain social roles (e.g. paid employment) and increased likelihood of spending time in solitary activity (e.g. watching TV). There are differences between older

and younger people with PD (i.e. above or below 65) both in the extent to which they engage in activities and in their responses to that situation. However, frequency of participation in activities was not reported.

Among people with PD, males of all ages and females under 65 are significantly more likely not to be in employment than the general population, PD having an influence on decisions to leave work for approximately half of those not in work (Singer, 1973; Oxtoby, 1982). Those not in work do not have access to the companionship that work may provide. The impact of this may be greater for younger males who also report fewer close friends and membership of formal organisations (Singer, 1973). Males with PD under 65 are also more likely to have an income lower than others in their age group and therefore fewer opportunities to compensate for the loss of work-based social contact.

In addition to social role loss and reduction in social participation (including entertainment such as cinema visits) involvement in activities arising from household roles and leisure roles is also reduced. People with PD are less likely to perform household chores without help or to engage in housework on an average day (Singer, 1973). However, they are both more likely to watch TV, to read and to engage in solitary activities such as napping on an average day and to spend more time in such activities when they do. People with PD are also less likely to be engaged in activities such as shopping and walking, less able to carry out activities of daily living (ADLs) and perform motor skills for tasks such as answering the telephone (Singer, 1974a). Singer suggests that this is

evidence of ‘premature social ageing’ since the social profile of those with PD is that of more elderly groups in the general population.

There is a degree to which social role curtailment and social disengagement is enforced by the physical limitations of PD. Oxtoby (1982) found that only 18% of people with PD were able to drive themselves and so were relatively more dependent on others to visit them in order to make social contact (although comparison data is not presented). Singer explores this further by considering intrinsic as well as exogenous factors. For example, in terms of symptoms of PD and absolute levels of activity the younger patients perform better than the older patients (Singer, 1974a). However, the younger group have a more negative evaluation of their health and illness than the older group, have fewer social contacts and report more stigmatisation. Singer hypothesises that this attitude to the illness is a cause of social withdrawal more powerful than the absolute severity of the illness itself.

The decline in social functioning present in those with PD is not reversed by treatment with levdopa despite the motor benefits the drug provides (Singer 1974b). Those social roles which had already been lost at the time that treatment began were not regained during the nine months of treatment. However, the factor which emerged as most likely to predict benefits of treatment was what Singer termed ‘sick role attitude’, meaning the ability to remain cheerful and accepting towards the illness.

Despite the limitations of these studies they do provide a starting point for exploring social interaction in PD in some more detail. Oxtoby explicitly acknowledges the deficiency of her study in relation to speech and intelligibility as mentioned above. The significance of this became apparent to her as it emerged from the data that difficulties with speech gave rise to many embarrassing, upsetting and isolating events for the participants. In discussing social participation neither author considers speech, language or discourse patterns as either contributing to or reflecting trouble in achieving successful social interactions. More recent studies which have explored this topic from outside the field of speech and language pathology have adopted a qualitative approach. These include anecdotal contributions from carers and patients which do not follow any particular methodology and which tend to focus more on the symptoms than the interactional consequences (e.g. Bluestone, 2005). Studies which use a systematic methodology often employ a structured interview technique to elicit data and a range of qualitative techniques to analyse them. In some cases these are specified in some detail e.g. Hodgson et al. (2004) justify their choice of a phenomenological approach to understanding the couple relationship in PD and include bias statements and details of their verification process. There is, therefore, some difficulty in comparing studies not simply in terms of the differences in the type of data they are gathering but also in knowing precisely how the interpretations have been constructed. Nevertheless, a theme which emerges consistently is that of social withdrawal, reflected through the preoccupations of each study: social withdrawal in contrast with the persistence of the couple relationship (Hodgson et al., 2004); associated with

perceived psychosocial incompetence (Caap-Ahlgren, 2002); relating to hiding of feelings and therapeutic outcomes (Sunvisson and Ekman, 2001). The experience of this social withdrawal is well-described through this literature and that which focuses on the impact of dysarthria in particular (see below). However, in accordance with the particular research questions asked and the methodologies employed, specific aspects remain uninvestigated because no data were collected relating to the quantity of social activity. These issues are the focus of the present study.

2.6.3 Role of the listener/interlocutor

The importance of the role of the interlocutor has been explored already to some extent in relation to intelligibility above. Here the focus of the discussion is on the impact of conversational partner behaviour at a more psychosocial level. The evidence suggests that listener behaviour can be both positive and negative. Speaker reports place listener behaviour high on their list of concerns (Whitworth et al., 1999; Walshe et al., 2009; Miller et al., 2006; Walshe and Miller, 2011), yet Whitworth et al., (1999) documented the strategies used by carers during interactions with others and also the carers' perceptions of communication difficulty and found that a large majority (89%) of strategies used by carers to deal with interactional difficulties were either facilitatory (problem solving and encouraging) or accepting (following the speakers' lead). A relatively small number (17%) were confrontational or avoiding. In these dyads the listener behaviour was positively adapted although, as in many aspects of communication in PD, there is considerable individual variability.

Listeners appeared to focus strategies on aspects of conversation such as turn taking and topic management rather than addressing global issues such as content or goals when dealing with difficulties. Kegl and Poizner (1998) also found positive listener adaptation in that, as motor severity increased, the interlocutors became more active in ensuring that the impaired communicator continued to participate in the conversation. However, the perception held by dysarthric speakers of the reactions of others to their speech is often less positive. Although the reactions of professionals were viewed by some favourably and some positive feedback on speech received (Walshe and Miller, 2011) the more typical perception was of being negatively evaluated and treated differently because of their speech (Walshe and Miller, 2011; Walsh et al., 2009). The relationship between impairment and interlocutor behaviour is therefore complex.

How we perceive the way that others appraise us is central to our self-concept and this is susceptible to negative change (Walshe, 2003). Where listeners expressed irritation dealing with dysarthric speakers this led to withdrawal of the speaker and this exclusion from conversations was associated with loss of dignity (Miller et al., 2006). It is not clear to what extent the behaviour of others, including nonverbal communication, is changed in interactions with dysarthric speakers, but the evidence shows that the perception of change is itself sufficient to influence speaker behaviour in terms of their willingness to engage in interactions.

2.6.4 Dysarthria, social activity and social participation

In recent years more literature on dysarthria in general and in Parkinson's disease in particular has focused on the activity/participation dimension of the ICF framework . Methods of gathering data have thus far adhered to the view that participation cannot be fully understood without reference to the perspective of the speakers themselves. That is, the experience of restriction of participation is as important as the external measurement of participation and this experience can only be fully understood by investigating the individual's perceptions of that phenomenon. Accordingly, methodologies have used self-report either in the form of interview or questionnaire rather than other report.

Interview-based studies.

Among the interview-based studies sampling was purposive in most cases as is appropriate to this type of methodology in order to gain a broad range of viewpoints. Appropriate exclusion criteria were also applied to avoid confounding effects such as depression or cognitive impairment (Walshe and Miller, 2011; Brady et al., 2011a; Brady, et al., 2011b; Dickson et al., 2008; Miller et al., 2006). Only Mackenzie et al. (2011) used a convenience sample which was due to the fact that their study was focused on dysarthric speakers' who had engaged with civic involvement rather than participation in a more general population. All the studies recorded and transcribed the interviews and took broadly similar approaches to analysis, applying a process of coding and categorising to extract themes from the data. Reliability checking of the analysis was reported by Walshe and Miller (2011) and Mackensie et al. (2011). All of

the studies used a semi-structured approach to interviewing although the degree of structure within the topic guides varied. Walshe and Miller (2011) and MacKensie et al. (2011) explicitly included dysarthric speakers' own accounts when developing topics for the interview. MacKensie et al's study is distinguished by its specific focus on civic involvement. Other studies display some areas of commonality and some areas of difference in terms of the topics they investigated. Topics addressed by all studies were life changes resulting from dysarthria, the effect of dysarthria on the person and the strategies that dysarthric speakers used to help their communication. Some studies explored the experience of the onset of dysarthria (Walshe and Miller, 2011; Miller et al., 2006) while some addressed employment and social situations (Brady et al., 2011a; 2011b; Dickson et al., 2008). Reflecting the fact that other disorders are frequently present alongside dysarthria due to the nature of common aetiologies such as Parkinson's disease and multiple sclerosis, Walshe and Miller (2011) also explored speakers' views on the significance of their dysarthria in the context of all their health and social concerns.

Some authors have investigated speaker self-concept where a diagnosis of dysarthria has been made (Walshe, 2003; Miller et al., 2008; Miller et al., 2011). These authors took a questionnaire-based approach using a semantic differential scale adapted first by Walshe (2003) from a scale used with people with head injury and subsequently by Miller and colleagues. Speakers were asked to rate themselves as a communicator on a series of bipolar constructs e.g. 'adequate – inadequate, sociable – withdrawn, caring – uncaring'. The

original scale, the Head Injury Semantic Differential Scale (HISD) (Tyerman & Humphrey, 1984) is reported to have good internal reliability and construct validity and to be sensitive to change following stroke as well as head injury. Four constructs from the original test were substituted with others following input from dysarthric speakers. Miller et al. (2008) used a large community-based sample of 176, 34 of whom were followed up for the later study (Miller et al., 2011). Participants were screened for cognitive impairment, depression, other communication impairment and were all first language speakers of English. Overall, qualitative investigations of psychosocial impact of dysarthria have therefore been well constructed.

Emergent themes

Themes that emerged from the literature included the following concerns for people with dysarthria:

- changes to communication which affect speech production,
- communicative activity and participation,
- differences in the way the speakers perceive that they are treated by others,
- barriers to communication of various forms,
- negative emotional experiences,
- impact on life participation.

Impairments to speech that were reported often focus on changes to voice rather than articulation. Lack of intonation (Walshe and Miller, 2011) and voice quality changes (Miller et al., 2006; Dickson et al., 2008) are specifically

mentioned in relation to dysarthria. However, the impact of changes to articulation may be felt in terms of reduced clarity or intelligibility which are also expressed as concerns for dysarthric speakers (Miller et al., 2006; Miller et al., 2011; Brady et al., 2011a). Changes affected the way in which speakers organised their attempts at communication. Some reported having briefer conversations, avoidance of particular words or communicative activities such as small talk (Walshe and Miller, 2011; Brady et al., 2011a) and difficulty getting a message across to listeners (Miller et al., 2011; Brady et al. 2011a). Avoidance of situations where speaking is required, in particular places and for particular tasks, was described as was avoidance of speaking to unfamiliar people (Walshe and Miller, 2011; Brady et al., 2011a). More challenging situations, such as speaking on the telephone where there is no visual support for speech, were avoided (Dickson et al., 2008; Brady et al. 2011) as was speaking in a group (Walshe and Miller, 2011; Brady et al., 2011a; Dickson et al., 2008). Compensatory strategies employed included selection of opportunities for non-speaking interaction such as using self-service shopping (Brady et al., 2011)

How dysarthric speakers manage their communication in social groups is complex. A characteristic tendency reported by speakers themselves is to become more passive as a communicator, allowing others such as spouses to do more talking for them (Walshe and Miller, 2011; Dickson et al., 2008; Miller et al., 2006) although this was sometimes forced upon them by the behaviour of others who spoke to their partner in preference to the dysarthric speaker (Brady

et al., 2011a). This passivity may be influenced by difficulties following the conversation (Dickson et al., 2008) but also by difficulties in performing interactional tasks such as taking the conversational floor at appropriate moments (Miller et al., 2006). At the same time there were differences in the views that dysarthric speakers took of others' talking for them, some finding it helpful (Dickson et al., 2008) while others felt demeaned by it (Brady et al., 2011). Not surprisingly, self-perceptions of social isolation, dissatisfaction with social activity and feelings of being more withdrawn were reported in most studies (Walshe and Miller, 2011; Brady et al., 2011; Miller et al., 2008; Miller et al., 2011; Walshe, 2003). Dickson et al. (2008) reported difficulty making friends and self-imposed social isolation among a group of dysarthric speakers of mixed aetiology.

An important issue that emerges from the various findings is the relationship between how others interact with the dysarthric speaker and that speaker's emotional response and feelings of self-worth. Speakers reported the experience and feelings of being treated differently because of their dysarthria and even of feeling stigmatised (Brady et al., 2011a), especially by strangers (Dickson et al., 2008a) although the presence of this belief was unrelated to the severity of the speaker's impairment. Dysarthric speakers reported negative non-verbal signals from unimpaired speakers (Walshe and Miller, 2011) and unwanted sympathy (Dickson et al., 2008). Feeling neglected or talked over in conversation in some cases lead to feelings of depression and lowered self-worth (Miller et al., 2006). Experience of negative emotion was reported by

many speakers. This was sometimes in the form of embarrassment which was related to specific speaking situations (Walshe and Miller, 2011; Dickson et al. 2008) or a more general negative evaluation of self-concept: perception of self as a communicator was associated with feeling more inadequate, incompetent and less in control (Walshe and Miller, 2011; Miller et al., 2008; 2011; Walshe, 2003).

It should be noted that deterioration in speech as measured by intelligibility was not a good indicator either of the emotional changes outlined above (Miller et al., 2011; Dickson et al., 2008) or of changes to the contributions to social interactions (Brady et al., 2011b). Indeed, even speakers whose dysarthria was mild enough for them to achieve normal levels of intelligibility found that the degree of concentration required resulted in a reduction in their capacity to have spontaneous conversations (Brady et al., 2011b). Thus, impact of dysarthria is not proportionate to severity of dysarthria.

Many speakers reported how changes to speech impacted on their sense of self and identity. Speakers reported feeling that when they sound different, they no longer feel like their former self (Brady et al., 2011a; Dickson et al., 2008). Indeed, more concerning than change in voice quality for speakers with Parkinson's disease was the impact of that change on self-image (Miller et al., 2006). It would appear that the speaker's perception that there had been a change was itself significant in affecting self-image and this was independent of severity of dysarthria. Constructs of self as a communicator worsened following

onset of dysarthria (Walshe, 2003; Miller et al., 2011) but where speech deteriorated significantly over a three year period there was no corresponding deterioration in self-perception as a communicator (Miller et al., 2011).

The work of Walshe (2003) and Miller et al. (2008, 2011) suggests that there may be changes to self-concept which are specific to dysarthria. While most constructs changed following onset, ratings of self for the semantic differentials 'intelligent – stupid', 'tense – relaxed', 'friendly – unfriendly', 'caring – uncaring' remained the same for speakers with PD when rated before diagnosis, subsequent to diagnosis and at three year follow up and it is suggested that these are core constructs which are independent of communicative change. It should be noted, however, that self-reports of self-concept prior to diagnosis of acquired communication disorders have so far, for obvious reasons, been restricted to recollection made following diagnosis. As Walshe (2003) notes, past self may be strongly related to ideal self and so self-evaluation following diagnosis may be adversely influenced by comparison with an idealised former state. The evidence for continuing change to self-concept as disease and speech severity significantly worsens was weaker (non-significant over the same period) although trending downwards (Miller et al., 2011). This may indicate that sense of self-worth associated with communication change is particularly sensitive close to the emergence of the first signs which may only be noticeable to the speakers themselves. Self-concept as a communicator may become more robust to continuing deterioration of speech as the speaker becomes more accepting of their situation generally.

A further theme emerging from the data published so far is that of perceived barriers to communication. It is recognised that these can be internal (Walshe and Miller, 2011; Brady et al., 2011a) as well as external i.e. attitudinal and environmental (Walshe and Miller, 2011; MacKensie et al., 2011). Although family members were identified as sometimes being a barrier, a number of facilitators also emerged: health professionals and some other communication partners were identified as supportive in communicating with dysarthric speakers (Walshe and Miller, 2011; Miller et al., 2006) and email opened up possibilities for communication previously unexplored for some (Miller et al., 2006). These barriers may contribute to the impact of dysarthria on life participation felt by some speakers. The latter is documented by Walshe and Miller (2011) as changes to family roles, to employment status and leisure activities experienced by a variety of speakers.

These studies focused on the insider perspective and suggest that the experience of living with dysarthria is felt as one of significant negative change to communication, communicative participation and participation in life roles. However, in the context of the general findings it is important to emphasise that considerable individual differences were observed. For example, individuals had very different views towards spouse/partners' talking for them, some disliking it and some finding it helpful (Dickson et al., 2008). There were also examples of individuals who viewed themselves more positively following onset of dysarthria (Walshe, 2003) and who viewed the effect of their dysarthria on family relationships as either positive or negative (Dickson et al., 2008). Clearly, where

data are collected for purposes of therapeutic intervention the individual profile must always be considered and it would be unwise to make any assumptions about the impact of dysarthria on any individual case.

An important and consistent finding was the perception among speakers that they were experiencing increased social isolation. Dysarthric speakers felt more socially withdrawn and dissatisfied with their social lives and social activities. Whilst this is undoubtedly part of the experience of living with dysarthria none of the studies published so far have documented changes in the levels of social activity or the size and composition of social networks quantitatively. The data so far show that the quality of social experience deteriorates following onset of dysarthria but the question remains unanswered whether reductions in the quality of social lives is associated with corresponding reductions in the quantity of social activities and contacts or the patterns of activity and communication across the social network.

Questionnaire Studies

A number of publications have attempted to extend dysarthria research into the area of social participation using questionnaire-based self reporting techniques (Ball et al., 2004; Donovan, 2005; Donovan et al., 2008; Hartelius et al., 2008; Piacentini et al., 2011; Walshe et al., 2009). All are studies of reasonable power and of reasonably robust design although the authors of all the studies indicate that further development work is being undertaken to improve the psychometric properties of each. Typically, a convenience sample was used, with the

exception of Walshe et al. (2009) who employed theoretical sampling to ensure a broad range of participants. Group sizes varied between 25 and 55 and exclusion criteria for cognitive impairment, depression and co-occurring communication disorder were applied in all cases. Only two studies (Donovan, 2005; Donovan et al., 2008) examined dysarthria in PD alone, the remainder recruiting a variety of dysarthria types including both progressive and non-progressive.

The questionnaires address different aspects of participation and related aspects of disability. For example, while Walshe et al. (2009) acknowledge the importance of social functioning, their instrument, the Dysarthria Impact Profile (DIP), focuses in greater detail on psychosocial consequences of dysarthria such as changes to self-concept and the extent to which the speaker has accepted their dysarthria. In contrast, the Communicative Effectiveness Survey (CES) (Donovan et al. (2008) focuses entirely on communicative effectiveness in a small range of situations and with a small range of communicative partners. This reflects differing aims of the respective authors. The DIP is intended to measure both social and psychological consequences of dysarthria. It is therefore explicitly not limited to assessment of participation and is intended to capture information relevant to the personal and environmental domains of the ICF as well. The DIP content aligns particularly well with the speaker concerns expressed in the interview-based research discussed above. In contrast, the CES is predicated on the theory that communicative effectiveness is a measure of societal participation and its application is restricted to participation within

the ICF. Both the Living with Dysarthria questionnaire (LwD) (Hartelius et al., 2008) and the quality of life in the dysarthric speaker questionnaire (QoL-DyS) (Piacentini et al., 2011) address a range of participation issues and both address situational communication challenges in more detail than the DIP but are more limited in relation to psychosocial reactions. The LwD includes items that address speech function, activity/participation, personal and environmental domains, i.e. all areas of the ICF and the authors emphasise the importance of the insider perspective when assessing impact of communication disorder. The QoL scale places less emphasis on the ICF as a framework, employing Quality of Life as its guiding principle but it is apparent that underlying concepts are convergent with the ICF to a large extent. The four sections of the QoL address speech characteristics, situational difficulty, compensatory strategies and perceived reactions of others and so address primarily speech function, activity/participation and environment although some individual items may be relevant to the personal domain as well. As with all the other studies, the authors assert the importance of the insights gained by collecting information from the perspective of the patients themselves.

There are some limitations in these existing measures in so far as they address participation. Indeed, the lack of a robust measure of participation has been acknowledged by a number of authors (Walshe and Miller, 2011; Walshe et al. 2009; Yorkston et al., 2008; Eadie et al. 2006). For example, although the CES aspires to measure communication for societal participation it is limited in that high numbers of its items cross multiple life domains and are not clearly

contextually or goal-defined. Note, however, that communication for societal participation and societal participation are not identical constructs. Communication is a valuable but not the only means by which we achieve social action (Simmons-Mackie and Damico, 2007). It is therefore possible that communication effectiveness can be rated as impaired but actual participation i.e. fulfilment of life roles, be formally unaffected (just as speech may be judged impaired but intelligibility remain unaffected). It should also be noted that unimpaired speakers do not rate themselves as maximally effective in all speaking situations using the CES (Donovan et al. 2008). In the absence of data which indicates how this finding relates to satisfaction or dissatisfaction with societal participation of unimpaired speakers it is not clear how fully ratings of communication effectiveness in dysarthric speakers describe participation. In addition, although the CES, the LwD and the QoL scales address a range of communicative situations and distinguish between familiars and strangers the focus is on effectiveness and extent of difficulty encountered, Therefore they cannot be used to determine how or in what way social lives may have changed as they do not collect data on the type of social activity undertaken, the frequency of occurrence or with whom it takes place. Furthermore, these scales do not collect data on how social networks are composed and the type of contacts that are made between members of the network.

The DIP similarly addresses a range of activities and interlocutors (telephone, shops, strangers) and asks the respondent to agree or disagree with statements which explicitly focus on alterations to social activity such as ‘My social life has

changed' and 'The difficulties I have with my speech restrict my social life'. However, it is not always clear whether responses indicate actual rather than perceived change. For example, although agreeing with the statement, 'The difficulties I have with my speech restrict my social life' implies a quantitative change, agreeing with 'My social life has changed' can be interpreted in both quantitative and qualitative terms; it may refer either to the frequency of occurrence or the quality of the experience. Similarly, agreement with the statement 'Because of my speech I have become socially isolated' may indicate that social contacts are few or that when in company the speaker experiences isolation due to difficulties participating fully in the activities of the company.

The existing literature demonstrates that while the ICF is a motivating factor in moving assessment into the area of participation there is still some lack of consensus about how to measure it and also that there are some aspects of participation which are not addressed at all. This point is also made by Yorkston et al. (2008) in an exploratory study of dimensions of participation in participants with multiple sclerosis. The dimensions they studied in relation to activities carried out by participants were (a) the importance of the activity, (b) the frequency with which the activity was carried out and (c) self-efficacy: the participants' confidence about their ability to participate in the activity. Both (a) and (c) are aspects of the subjective experience of dysarthria. In relation to dysarthria research both qualitative and quantitative data gathered so far including design of instruments for measuring participation have clearly focused on importance and self-efficacy but there has been no report of data relating to

frequency or range of social activities in detail. Walshe and Miller (2011) recently stated the urgency of the need to extend the data that is currently available from interviews and surveys such as the CES into areas such as social networks and participation patterns. Indeed, therapeutic approaches such as that described by Bereskin and Craig (2009) are predicated on a need to strengthen social networks which they associate with maintaining quality of life..

In conclusion, no single measure has been developed which comprehensively assesses social participation in dysarthria but there is a range of evidence which suggests that it is reduced. Existing literature provides tools in the form of, for example, ratings of communication effectiveness, which can indicate the speaker's perception of their communicative resource for participation, and there is a growing body of qualitative work documenting the perceptions of PD speakers themselves which provides valuable insight into the experience of changes in social communication and provides a focus for designing measures of relevance to intervention. There is a lack of research evidence describing the extent of and type of social activity and the size and composition of social networks and this, therefore, is the focus of the current study. Further motivation for gathering such quantitative data is set out below.

2.7 Quantifying social lives: social capital of people with impaired communication

Qualitative aspects of social integration in people with motor speech disorders have received attention in the literature described above but quantifiable dimensions such as number, type and frequency of activities, scale and

composition of social networks have not. Social network analysis developed during the twentieth century as an approach to understanding social action initially within the field of anthropology. Approaches to network analysis can be focused on the individual and all the connections that they have or on a defined group and all the connections between members of the group depending on the goals of the research. A number of different tools have been used to understand social networks such that it can be said that social network analysis is not so much a body of theory but 'an orientation to the social world that inheres in a set of methods' (Scott, 2000, p37). The key point is that the choice of a particular method has a logical sociological rationale.

A social network may provide different types of support including emotional and instrumental support and there are several ways in which networks can be understood in relation to this. Network connections can be understood in terms of exchange of services between members, in terms of the role relations which are present such as familial or organisational structures and in terms of the subjective intimacy of the relationship (Phillipson, Bernard, & Phillips, 2001). The latter can be termed the *affective network* and has a particular advantage when investigating the network of a focal individual in that it does not privilege either the exchange of services or selected relationships such as family ties but allows the network membership to be entirely determined by the focal individual. It therefore embodies the insider perspective. The affective network can be captured by the convoy model (Antonucci and Akiyama, 1987, and see appendix 14). In this model the network is not organised by spatial or structural

dimensions but according to the perceived importance of the network member to the focal individual. Aspects of relational data, proximity and nature of contact may additionally be captured but the degree of importance in the life of the focal individual determines the choice of members and their position in the network. This is particularly important for research into older people in the UK as Phillipson et al. (2001) have shown that relationships beyond the family have become more important to this group during the last fifty years. Social network size is not affected by age in men but for older women composition is influenced by educational attainment (Ajrouch, Blandon, & Antonucci, 2005).

The value of documenting quantitative social data in relation to people with acquired language disorders has been asserted elsewhere (Simmons-Mackie, 2008) and in the field of aphasia a number of studies have been published which investigate these issues (Code, 2003; Hilari and Northcott, 2006; Cruice et al., 2006; Hilari et al., 2010; Vickers, 2010; Northcott and Hilari, 2011). Findings relate to overall size, to specific relationships explored within the data and to attitudes towards levels of activity. For example, reductions in the total size of social networks and the number of social activities have been reported following onset of aphasia (Cruice et al., 2006; Vickers, 2010; Hilari et al., 2010) as might be expected following unresolved disruption to communication. However, not all relationships are equally affected. Friendships, as opposed to family contacts, are especially vulnerable during the period after onset of stroke and presence of aphasia contributes particularly to this pattern of loss (Hilari and Northcott, 2006; Northcott and Hilari, 2011). This has special significance

because while the families of older people are central in providing practical support it is friends who often take the role of confidante and companion (Wellman and Wortley, 1989). Severity of aphasia is relevant to the changes observed. As severity of aphasia increases this has a negative impact on the number of hours spent in social and community activity (Code, 2003). Although presence of aphasia itself is not associated with psychological distress, satisfaction with one's social network is (Hilari et al., 2010). Of great importance here is the finding that health-related quality of life was highest following a stroke in those whose social network was maintained at the pre-stroke level, the absolute size of the network being unimportant. There is thus a growing body of evidence that in chronic illness, especially where communication is affected, extent of social engagement should be monitored and may be an appropriate target for intervention.

The literature referred to above indicates the value of examining a range of quantifiable social variables, all of which can be captured by the wider concept of social capital. It is argued that social capital provides a unifying construct in which the positive and negative relationships between health and social measures can be explained. There is now an extensive literature on social capital (see Putnam, 2000 for an accessible survey of the area) and, although criticised for lack of specificity e.g. Harper (2001, 2002) there is sufficient agreement on central concepts (Field, 2008). However, defining social capital, a multidimensional concept, is problematic.

Some writers view social capital in primarily economic terms. For example Bourdieu (1985) describes it as the benefits accruing from connectedness and which arise both from the relationships which give access to resources and the resources themselves. Although analysis of social networks is identified as central to understanding social capital (Burt, 2000) the focus falls on the instrumental benefits of network membership operating according to market dynamics. While this interpretation may account for social network relationships within employment situations it has limitations when applied to the wider population. People with PD are commonly either beyond working age or leave employment at some stage during their illness. The resources accessible through the social networks to which these people belong are more likely to involve quality of life dimensions, some of which are specific to the health consequences of the condition itself, and less likely to emphasise purely instrumental gains.

Characteristics of social capital identified by Putman are both structural and cultural. Examples of structural social capital are civic and personal networks and engagement in the processes of those networks. Examples of cultural social capital are sense of belonging to a community and norms of trust between members, reciprocity and cooperation. Social capital can also be characterised as bonding or bridging and this distinction illustrates the potential of social capital to be harmful as well as beneficial. Bonding social capital is essentially exclusive, offering advantages to members of a group by restricting its functions only to that membership. The effect of this is to reduce

cohesiveness in the wider population which increases the burden of transactions and raises costs. Notably, bonding social capital is associated with greater health costs (Svendsen and Svendsen 2004). Bridging social capital, in contrast, is primarily inclusive and is associated with social and economic benefits which derive from increased trust and cooperation. Definitions of social capital must therefore take account of a wide range of relationships but the well-established associations with poorer health outcomes (for reviews see Islam, Merlo, Kawachi, Lindström, & Gerdtham, 2006 and MacKinko & Starfield, 2001) indicates the importance of a valid measure.

For the purpose of measuring social capital in order to understand its relationship to health Pilkington (2002) recommends the UK Health Development Agency (HDA) guidance (Coulthard, Walker, & Morgan, 2002) which uses indicators for five aspects of social capital: civic engagement; neighbourliness; social networks; social support; perceptions of local area. Bates and Davis (2004) follow the HDA's Social Action Research project model of social capital (Ford, 1999) which further emphasises feelings of trust and safety in the community but make explicit also the links between the formation and maintenance of social capital and social inclusion. For example, a social capital-centred view of volunteering will emphasise the inclusion benefits which are created in the form of affiliation and membership in the community rather than the purely instrumental benefit of volunteering as preparation for employment.

It may be useful to note here that both structural and cultural aspects of social capital are underpinned by communicative ability which facilitates participation in networks. The role of communicative skills in building interpersonal networks has long been recognised (Phillipson et al., 2001). Although social capital is not defined solely by dimensions of social networks (as can be seen from the above, the dynamics of the relationships are important too), features of the network such as size, density and frequency of contacts can serve as useful indicators of social capital (Franke, 2005).

In this study measures of social network and social activity capture key aspects of structural social capital which may have either bridging or bonding effects. However, cognitive aspects of social capital are not explored as the primary goal of the project is to understand extent and type of social participation rather than perceptions of relationships. This issue is discussed further in chapter 8 section 8.4.

2.8 Summary of Literature Review and Research Questions

The literature review has introduced the topic of dysarthria within the context of motor impairment arising in Parkinson's disease. Much of the earlier research in this field has focused on describing the nature of the speech impairment, either perceptually or acoustically. The literature has also investigated the impact of changes to speech performance on intelligibility which has been considered to be the most important index of the severity of dysarthria. The strengths and limitations of intelligibility as a construct have been discussed, notably the relative dearth of studies which have investigated how participants in naturally-

occurring conversation achieve communicative success where intelligibility is compromised. More recently, in the context of greater interest in the biopsychosocial model of illness and wellbeing, ICF, (WHO, 2001), a number of studies have explored the psychosocial impact of dysarthria from the perspective of the speaker. A number of important findings have been made. One of these is that the predictive value of intelligibility in relation to psychosocial impact is highly questionable. Indeed, intelligibility may remain within normal limits where anxiety about speaking has already developed and inhibits interaction. Speakers with dysarthria commonly express the view that they have withdrawn socially at some level and that social participation has been negatively impacted by dysarthria where both personal and environmental factors play a part in reducing the quality of conversation. The recent research has focused on the quality of the social experience of people with dysarthria, which is rightly a priority. Other studies have developed measures which address social participation but none of these satisfactorily capture all aspects of social participation. The literature has not, so far, explored the quantity, type and frequency of social activities or social network contacts. These variables, in the current study, have been construed in terms of the social capital of the speaker. In another area of acquired communication impairment, aphasia, such variables have been found to be significantly affected by the presence and severity of the communication disorder.

The study aimed to investigate the relationships between dysarthria and particular aspects of social participation relevant to social capital, to test the

hypotheses that levels of social activity and network size for people with dysarthria arising in Parkinson's disease would be lower than those of a matched group of non-neurologically impaired people and that degree of speech impairment would also impact social participation negatively and to explore the accounts of change to social life given by speakers with dysarthria.

Specific hypotheses, based on the study of the literature described above were as follows:

Hypothesis 1

Levels of social participation in terms of social anxiety, social activity and social network dimensions for a sample of people with dysarthria arising in Parkinson's disease will be lower than those of a matched group of non-neurologically impaired people.

Hypothesis 2

Levels of social participation in terms of social anxiety, social activity and social network dimensions for a sample of people with dysarthria arising in Parkinson's disease will be negatively impacted by severity of dysarthria.

3 Chapter 3 Method

3.1 Introduction

Investigations of participation in dysarthria have either focused on the psychosocial impact of the disorder from the perspective of the lived experience of the individual or have measured the speaker's perception of their own communicative effectiveness or similar as a proxy for communicative participation. In contrast, this study was designed to investigate the number, type and frequency of social activities and social contacts with a view to understanding shifting patterns of change that might occur in these variables as speech deteriorates in the context of Parkinson's disease. In addition, and recognising that concerns about communication may precede overt deterioration in speech, the study was designed to capture information relating to anxiety about speaking. Data was therefore gathered relating to social activity, social networks and social anxiety. Existing questionnaires were used to enable comparison with previous studies where appropriate. The perceptions of speakers regarding nature and causes of changes to social life were also investigated in order to provide an insider perspective on social changes captured by quantitative measures. The research philosophy underpinning the study would best be described as critical realism, the rationale for the study being an effort towards understanding how dysarthria impacts social participation from both external and internal viewpoints.

3.2 Aims

The study was designed to test the hypotheses that levels of social activity and network size for a sample of people with dysarthria arsing in Parkinson's disease would be lower than those of a matched group of non-neurologically impaired people, also that degree of speech impairment would impact social participation negatively. The study further aimed to gather and explore the accounts that speakers gave of changes to their social lives in relation to quantitative data findings.

3.3 Rationale for Research Design

An underlying and essential feature of all research should be coherence between the research questions posed and the methods and approaches used to investigate it. Features of research questions which support coherence include an appropriate narrowness of focus, relevance to practice or policy, situating the investigation appropriately within the existing knowledge and practical feasibility (Lewis, 2003). Each of these points will now be addressed in relation to the present study.

The question that is posed seeks an explanation of the relationship between speech impairment and social life. An investigation of this question using only closed, quantitative instruments could offer a relatively narrow description of the phenomena being investigated. A research design which includes both quantitative, questionnaire-based data collection and also qualitative analysis of interviews with participants therefore offered greater breadth while remaining focused on the central question. The quantitative element of the study

addressed principally questions of structure of social life while the qualitative element was able to illuminate processes operating within that field.

The research question is of relevance to clinical practice and to the population sampled in that it is hoped that the results will increase understanding of assessment of communication impairment and social participation although it is acknowledged that the nature of the study may limit generalisation. It is anticipated that the study will also add to theoretical understanding of the relationships between illness, communication impairment and social participation. The research question is motivated by an absence of quantitative data describing social participation in the sampled population (as detailed above in the literature review). The feasibility of the study has been matched to the resources available to the researcher, a part-time post-graduate student. This imposed some constraints on the project in that data collection and analysis was confined to a single researcher and so interaction rather than independence of the two aspects of the study throughout the design and implementation of the project was necessary.

As suggested above, a suitable research design to investigate the research questions involves mixed methods, both quantitative and qualitative. It is not clear yet how quantitative measures of social participation are influenced by other factors which may impact on social behaviour such as communication impairment and other impairments which restrict actions necessary for functioning. In a condition such as PD which affects speech and non-motor

functions as well as motor performance the relationships between contributing factors are likely to be complex and therefore the perspective of the participants, accounts from within the situation of what impacts on social life and how, is likely to add meaning and power to interpretations of quantitative data taken from the same sample (Plano-Clark and Creswell, 2008).

Combining quantitative and qualitative data collection and analysis can be done in a range of ways and for different purposes which have been elaborated by a number of authors (Tashakkori and Teddlie, 1998; Morgan, 1998) The purpose of using a mixed design in this study was neither corroborative nor initiatory in the typology of Rossman and Wilson (1989) as the intention of including a qualitative element was to enrich interpretation of the quantitative data. In Rossman and Wilson's typology the purpose of the study is therefore closest to 'elaborative'. However, a more detailed and influential typology of mixed methods designs was proposed by Greene et al. (1989) and the purpose of this study follows most closely their recommendations for a design that seeks complementarity, where clarification of the results from one part of the study is supported by the results from the other part.

Greene et al (1989) suggest that the issues to consider in designing mixed methods studies are the extent to which methods being used are similar or different, the extent to which the phenomena being investigated by each method are similar or different, the paradigms employed, the relative prominence within the study of each method, the extent to which

conceptualisation, data collection and analysis are managed independently for each method, whether implementation of each aspect of the study occurs sequentially or concurrently and whether the project consists of a single or multiple studies. The purpose of the study will shape the decisions that are made regarding each of the above issues. Greene et al (1989) describe the design characteristics of a complementarity study as: difference in methods used in each part; that the phenomena investigated in each part are overlapping, that is they are facets of the same phenomenon; that the parts of the investigation may differ in prominence but should not have greatly unequal prominence; that design and implementation of both methods may involve all researchers at all stages; data collection is concurrent ; the project involves a single study. This study adheres to this template and differs from a pure triangulation design in that there is no special emphasis on convergence between the two sets of results; the phenomena under investigation in each part of the study are related but different aspects of the social lives of participants. Another characteristic of a complementary mixed methods design is that both parts of the study share a research paradigm, meaning that the underlying ontological, epistemological and methodological assumptions that guide the researcher apply to both parts of the study. As this is a prominent issue for mixed methods research this is discussed separately below.

Research Paradigm

Within mixed methods research quantitative and qualitative data collection and analysis are combined. This presents an epistemological problem in that quantitative and qualitative investigations operate under different research paradigms. Quantitative research is typically associated with positivist/empiricist approaches to understanding the nature of reality and knowledge which assume an external, objective reality governed by laws which it is the aim of research to uncover, and employing a process of deductive reasoning in theory or hypothesis-driven investigation. In contrast qualitative research is strongly associated with constructivist/phenomenological approaches in which the logic of inquiry is based on subjective, individual accounts of experiences using inductive reasoning and data-driven methods to generate theory de novo (Guba and Lincoln, 2005). Strong versions of either epistemological stance view the knowledge generated by the each paradigm as incompatible with the other paradigm and therefore both positivist and constructivist stances cannot be incorporated in the same study meaningfully (Guba and Lincoln, 2005). However, an alternative paradigm has been proposed which does not privilege the ontological and epistemological assumptions but focuses instead on the methodological challenges to combining data types in relation to research questions (Morgan, 2007). This paradigm is pragmatism.

Pragmatism offers an alternative to the all or nothing opposition of inductive versus deductive reasoning, subjectivity versus objectivity, context dependent

versus generalisable knowledge which characterised earlier argument about research paradigms. Pragmatism follows a logic of inquiry which recognises and encourages methods of bringing together meanings from different types of data. For example, abductive reasoning is employed rather than purely deductive or inductive reasoning. This permits movement between theory and data such that the results of qualitative inquiry can generate hypotheses that can be tested quantitatively and the constructs tested by quantitative methods can be explored further by qualitative research. In practise, this occurs all the time in health research even in single method studies since quantitative researchers use data to refine theory and qualitative research does not occur in a theoretical vacuum. The strong version of the dichotomy between deductive and inductive reasoning is false. This is true also of the dichotomy between absolute objectivity and subjectivity. In practise, in the social world we constantly move between internal and external frames of reference to achieve shared meaning. Pragmatism, in adopting inter-subjectivity, recognises that there may be both a single reality and multiple perceptions of that reality which guide people's actions. Similarly, transferability breaks down barriers between views of knowledge as entirely context-dependent or generalisable by focussing on communicating effectively those things which are generalisable from the individual context and those contexts in which general rules break down. In effect pragmatism re-offers the traditional dichotomies as continua so that the researcher may position him/herself at some moderate place between extremes.

Pragmatism as a research paradigm is based on the existence of shared beliefs about the nature and values of research which overarch the specific stances of positivism/empiricism and contructivism/phenomenology. In respect of this study there was no conflict between the two parts of the study in terms of the broader aims which were to increase understanding of an aspect of human health and well-being and to communicate the results to shape clinical decision-making. In conducting mixed methods research it is necessary to retain the principles of quantitative and qualitative research during design and implementation of their respective stages. However, compatibility can be achieved during interpretation if it is accepted that different theories can be used to explain or illuminate any particular set of results (Reichardt & Rallis, 1994). There is sufficient similarity between the orientations of post-postivist quantitative researchers and qualitative researchers to allow this.

Overview of Design

Following the discussion above the type of research design chosen was a mixed methods concurrent design. The principal methodology was quantitative with a strong qualitative complement. The investigation recorded levels of social activity, social network and social anxiety in speakers with dysarthria arising from PD and a matched group of non-neurologically impaired control participants. Interviews were conducted concurrently to generate participant perspectives on changes to social life since onset of PD and to explore their experience of such changes. A concurrent rather than sequential design was

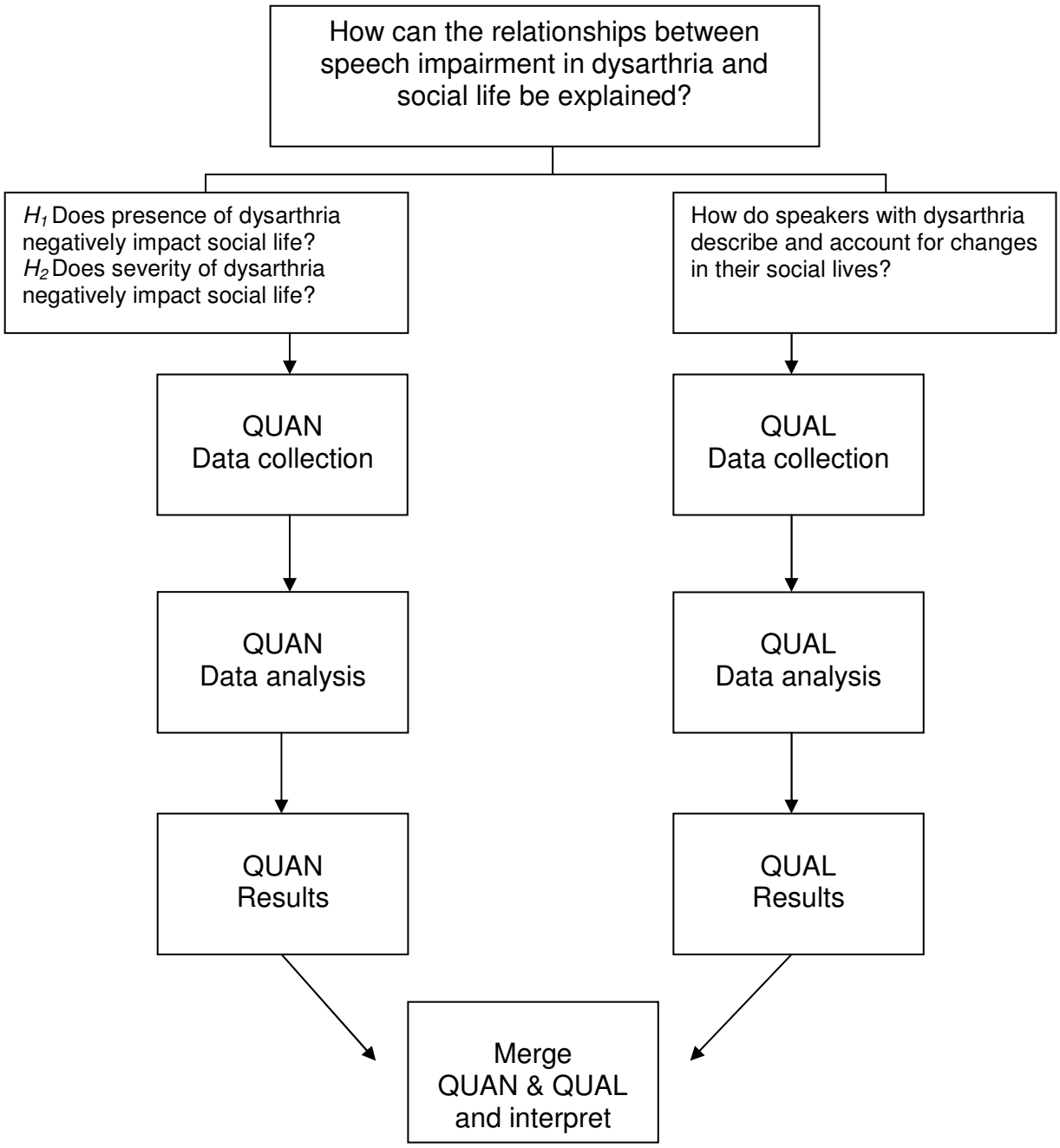
preferred as it was planned to represent as wide a range of participant accounts as possible rather than select cases based on quantitative findings. The quantitative data collection received higher prominence than the qualitative primarily because the literature revealed this to be a more obvious gap in existing knowledge. However, by interviewing all participants and including all transcripts in the data set for qualitative analysis the researcher ensured that this aspect of the study was not confined to a minor role. Integration of methods took place in framing the research questions and to some extent during analysis of data. For example, use of discriminant function analysis took place following multivariate analysis of variance and the conceptualisation of the functions generated was influenced by the thematic analysis of the interview data. Integration substantially took place during interpretation of both data sets. The research design and its relationship to the research questions is outlined in figure 3.1

3.4 Participants and Recruitment

3.4.1 Parkinson's Disease Group

The population under study were people with a diagnosis of idiopathic Parkinson's disease in contact with PD support groups in the East Midlands. Contact was made initially with the Parkinson's Disease Society/Parkinson's UK local organisers through whom volunteers were recruited (see appendix 1) and data collection took place during two periods. The first was in 2008-10 and the second, to increase the sample size, during 2012-13.

Table 3-1 Overview of Design and relationship to research questions



It should be stressed that, in order to address the research questions, it was not the aim of this study to recruit a sample representative of the wider PD population. Indeed, because the research project was attempting to isolate the

effect of dysarthria on social variables and therefore controlled possible confounding impairments which are often present in PD, cognition, physical functioning, depression, anxiety and apathy, the sample could only represent a sub-set of people with PD. For example, major depression is positively associated with social anxiety in PD (Kummer, Cardoso, & Teixeira, 2008). Nevertheless, the composition of this sample bears investigation in order to be able to understand and explain the findings of the study. A particular issue of interest is the sampling method in relation to the social variables that are being studied as it is possible that members of support groups may share particular characteristics.

Participants had to satisfy the following inclusion criteria to eliminate confounding effects which could influence social participation:

- No previous or co-occurring neurological problem
- No previous communication problem
- No psychiatric problem
- Passes screening test for cognition, apathy and depression
- Literate
- L1 English speaker
- Over 18 years
- Living at home and not housebound

In order to avoid the effects of confounding variables in the analyses to test the research questions, the groups of participants with PD and without PD were controlled for age, gender, education and socioeconomic classification (see section 4.6). In order to understand how the sample relates to people with PD as a whole, these variables were investigated further. The mean age of this

sample at onset of PD was 60.4 years (sd 11.1) which falls within the range of 56-72 years found by (Twelves et al., 2003). Although UK studies reviewed by Twelves et al did not publish age of onset means, the figure for the present study is similar to those for northern European nations in the review (61-65yrs).

Gender balance in the sample is very similar to published data for incidence of PD (Wooten et al., 2004; Van den Eeden et al., 2003 and see section 4.6). Educational attainment and socioeconomic status for this sample are both higher than UK norms (see section 4.6) and this must be taken into account when interpreting the findings. Recruiting from support groups with this profile may be thought to bias the sample, especially if support groups are prone to be populated by people with particular characteristics or behaviour in relation to social activity.

There is relatively little data published on the composition of PD support groups or the reasons that people join them. However, there is a wider literature reporting on support groups for a range of conditions including aphasia (Code et al., 2001). Comparisons between support groups should be treated with caution although there are similarities which have been shown in studies which compare multiple types of illness support groups (Davison et al., 2000, Maton 1988). Motivations for joining groups unsurprisingly include perceived benefits such as seeking information and support and members tend to have fewer access barriers, such as availability of time and transport (Biegel et al., 2004; Code et al., 2001). In some cases, disability attendant on a medical condition

makes full participation in certain activities impossible, especially sporting activities and this may be a driver towards support group attendance (Haslam et al., 2008). There may also be a desire to be with others who share the same predicament (Davison et a.,l 2000; Deans et al., 1988). More unexpectedly, attendance at support groups is not predicted by factors which indicate a predisposition to be a 'joiner' such as membership of other groups or friendliness of the participant or high use of other services (Biegel et al., 2004; Davison et al., 2000). In fact, an important impetus to join may be lack of social support in existing networks rather than an inclination to join groups (Tijhuis et al., 1998; Taylor et al., 1986). Davison et al. (2000) suggests that support groups are most attractive to those whose social identity has been put at risk and it is proposed that finding a shared social identity through the support group can be a buffer to this threat (Haslam et al., 2008). So while it is reasonable to suppose that support group membership may be a replacement for loss of other contacts evidence is lacking to support the proposition that support group members are particularly socially active. Members of self -help groups for aphasia were relatively less severely communication-impaired (Code et al., 2001) and therefore it is possible that communication ability is a factor in decisions to attend groups.

In a lifelong, chronic illness such as PD, the reasons that people attend a support group may be different at different times as the extent and nature of the impact of the condition will vary at different stages (Maton, 1988). It is likely that the motivations for joining a support group are complex and may involve the

nature and presentation of the illness, individual differences of various kinds and cultural norms (Davison et al., 2000). It would be unwise, therefore, to make assumptions about the characteristics of this sample based on their membership of support groups as the diversity of such memberships in a variety of medical conditions is evident from the literature. This is reinforced by the very wide range of social activity and social network levels found in this sample (see section 5.2) which demonstrate the diversity of the sample in social terms (although as noted above the educational and socioeconomic status of the sample must be considered).

3.4.2 Control Group

A matched control group of non-neurologically-impaired people were recruited by approaching local organizations in the same way. Inclusion criteria were identical and participants were selected to match groups for age, sex, occupational group and education.

3.4.3 Inclusion criteria

Participants had to satisfy the following inclusion criteria to eliminate confounding effects which could influence social participation:

- No previous or co-occurring neurological problem
- No previous communication problem
- No psychiatric problem
- Passes screening test for cognition, apathy and depression
- Literate
- L1 English speaker
- Over 18 years
- Living at home and not housebound

3.4.4 Biographical Data

Data was collected for the following variables in order that groups could be matched so that possible confounding variables could be controlled for (see also tables 2 and 3):

- Age
- Sex
- Educational level completed
- Socioeconomic status based on occupation (Market Research Society, 2006)
- Duration of Parkinson's disease
- Degree of physical impairment

Details of symptoms and medical history in participants with PD are also presented here (see table 3-4)

Table 3-2 Demographic data, control participants

Participant	Age	Sex	Socio economic status	Education
C1	72	F	C1	2
C2	73	F	C1	1
C3	65	F	C1	3
C4	80	M	B	1
C5	69	M	C1	1
C6	74	M	C1	2
C7	75	M	B	4
C8	77	M	C1	2
C9	48	M	B	3
C10	53	M	B	4
C11	63	F	C1	1
C12	61	M	C1	3
C13	54	M	C1	2
C14	69	M	C2	1
C15	61	M	C1	1
C16	67	F	C2	4
C17	81	M	D	1

C18	74	M	C1	2
C19	80	F	C2	1
C20	66	M	C2	1
C21	64	M	C1	1
C22	80	F	C2	2
C23	66	M	C1	3
C24	64	M	C1	3
C25	80	F	D	1
C26	73	M	C1	2
C27	89	M	C1	4
C28	77	F	C2	2
C29	67	F	C1	2
C30	76	M	C1	2
mean	70.9			*1 completed by 16*
stdev	9.5			*2 completed by 18*
				3 undergraduate
				4 post-graduate

Table 3-3 Demographic data: participants with PD

Participant	Age	Sex	Socio economic status	Education
P2	77	M	B	3
P3	79	M	B	3
P4	83	F	C1	2
P5	84	F	C1	1
P6	63	M	C1	1
P7	76	M	C1	1
P8	54	M	C1	1
P9	75	M	B	1
P10	59	F	B	4
P11	70	F	C1	1
P12	73	F	C1	1
P13	56	F	C1	2
P14	74	M	C1	1
P15	55	F	C1	2
P16	58	M	C1	2
P17	58	M	C1	2
P18	66	M	C1	1
P26	66	M	B	3

P35	81	M	C1	2
P36	83	M	C1	3
P37	64	M	C1	1
P38	69	F	C1	1
P39	68	M	C1	1
P40	56	F	C1	2
P41	53	M	B	1
P42	63	F	C1	3
P43	69	M	B	2
P44	72	M	B	3
P45	75	M	C1	2
P46	72	M	C1	1
P51	72	F	C2	1
P52	75	M	C1	3
P53	70	M	C1	3
P54	64	M	C2	2
P55	78	M	C2	2
P56	82	M	C1	3
P57	72	M	C1	2
P58	75	M	C2	1
P59	66	F	C2	3
P60	67	M	C2	1
P61	59	F	C2	2
P63	58	F	C2	1
P64	80	F	B	2
mean	69.1			
stdev	8.9			*1 completed by 16* *2 completed by 18* *3 undergraduate* *4 post-graduate*

Table 3-4 Medical information, participants with PD

Part.	Duration PD (months)	Mobility (PADLS)*	Non-speech symptoms	Medication for PD symptoms	Co-morbidities and medical history.	Other medications
P2	84	2	Bilateral tremor in arm and leg, micrographia, posture and gait impaired	Ropinirole, Sinemet plus	Lower back pain	
P3	108	4	Bilateral rigidity in legs, difficulty walking	Madopar, Sinemet	Blind in left eye	
P4	72	4	Bilateral freezing in legs, frequent falls	Levadopa, Benserazide, Ropinirole	Cataracts restored 2002	
P5	72	4	Bilateral tremor in legs, stiffness, falls	Sinemet, Mirapexin	Hypertension Macula degeneration	Atenolol, Benzoylfluoride, Amlodipine
P6	228	3	Bilateral tremor, rigidity and bradykinesia,	Madopar, , Tamazepam	Thyroidectomy 1968	Atropine
P7	36	3	Tremor in left arm, hand skills impaired, balance impaired	Madopar	Hypertension	
P8	54	3	Rigidity in left leg and arm, tremor, gait affected, fatigue	Stalevo, Rotigotine, Rasagiline,	Atrial fibrillation	Sinstatin
P9	60	2	Tremor in left arm and leg, impaired gait, urinary frequency	Pramipexol, Carbidopa, , Tolterodine	Back pain since 2006	Tonapan
P10	120	3	Bilateral tremor in arms and legs, posture and gait impaired. Bowel and bladder affected	Sinemet, Mirapex, Amantodine, Oxybutynin, Lactulose	Nil	
P11	60	4	Tremor in right arm and leg, impaired gait	Sinemet, Stildem	Angina, arthritis, hypertension, high cholesterol, insomnia	
P12	126	2	Tremor in left arm, reduced dexterity	Madopar, Entacopone	Knee replacement 2006	
P13	228	3	Bilateral rigidity and tremor	Madopar,	Back pain since 2006,	

				Sinemet	restricted mobility	
P14	16	2	Tremor in left arm, fatigue, restless legs, intermittent tremor in right arm, falls	Stalevo, Pramepexole	Basal melanoma removed, radiotherapy 1987	
P15	114	2	Bilateral rigidity in hand and arms, dyskinesia.	Madopar, Stalevo, Ropinirole, Sinemet, Amantadine, Baclofen, Clonazepam, Diazepam,	Hypothyroidism Knee replacement 2005	Thyroxine
P16	78	1	Tremor in right side	Trihexyphenidyl, Sinemet, Ropinerole	Nil	
P17	5	3	Rigidity in left side affecting gait, posture, balance	Rotigotine,	Hypertension, arthritis affecting mobility	Amlodipene
P18	96	3	Bilateral tremor in arms, impaired gait, fatigue	Cocareldopa, Ropinerole, Trihexphenidyl, ,	Diabetes, Hypertension	Gliclazade Felodipine
P26	94	2	Right arm tremor, micrographia	Madopar, Sinemet, Ropinerole	Nil	
P35	48	2	Tremor in right arm, micrographia,	Madopar	Spinal injury 2008	
P36	24	2	Bilateral rigidity in legs, impaired gait and balance	Stalevo, Rotigotine	Hypertension	
P37	157	3	Tremor in right arm	Madopar	Nil	
P38	164	2	Rigidity in neck and arms, tremor, dyskinesia, balance impaired	Selegiline, Stalevo, Pramepexole	Hormone replacement therapy	
P39	60	2	Tremor in left arm, stiffness	Stalevo,	Arthritis	Azathioprine
P40	204	2	Bilateral rigidity in arms and legs affecting fine motor control, freezing, fatigue	Apo-go pump, Sinemet, Madopar, Clonazepam,	Nil	
P41	60	3	Tremor in left arm, bradykinesia	Mirapexin, Azilect,	Hypertension	Propanolol
P42	149	2	Left arm and hand tremor	Sinemet, Ropinirole, Entecapone	Nil	
P43	70	2	Tremor right arm, micrographia, bradykinesia	Pramipexole, Madopar, Amantadine, Rasagiline	TIA 2005 affecting right side	
P44	72	2	Rigidity left arm, tremor, impaired gait	Madopar, Clonazepam	High cholesterol, Bowel cancer 2007	

P45	180	2	Bilateral tremor, rigidity, bradykinesia, impaired gait and balance	Madopar, Amantadine, Ropinirole, Sinemet, Acetaminophen	Angina	Atenolol
P46	84	3	Bilateral arm and leg, impaired gait and writing, incontinence	Madopar, Cocodamol, Tolterodine	Nil	
P51	212	3	Bilateral rigidity arms and legs, head and neck, tremor, dyskinesia	Stalevo, Pramepexole	Nil	
P52	122	2	Bilateral rigidity arms, dyskinesia on left, pain.	Madopar, Clonazepam	Weight loss, fatigue (no diagnosis)	
P53	148	2	Bilateral in arms and legs, dyskinesia, impaired gait and falls	Ropinirole, Sinemet, Madopar, Levadopa	Mild head injury 2011, no lasting symptoms	
P54	50	3	Tremor in left arm and leg, bradykinesia	Stalevo, Rotigotine	Subthaler joint fusion 2010	
P55	62	2	Bilateral tremor arms and legs, bradykinesia	Madopar, Azilect, Rasagiline	Fibrosis of lungs, prostate enlargement	Tamsulosin
P56	132	2	Bilateral arms and legs, impaired gait	Ropinirole, Sinemet	Chronic back pain	
P57	124	2	Bilateral tremor and rigidity affecting walking and eating	Madopar Pramepexole, Amantadine	Colonectomy 2012	
P58	130	3	Tremor in left arm and leg, impaired gait.	Stalevo, Rasagiline, Ropinirole, Amantadine, Clonazepam,	Lower back pain Enlarged prostate	Finasteride
P59	172	2	Bilateral tremor in arms, sleep disturbance	Sinemet, Ropinirole	Nil	
P60	173	3	Rigidity left side arm leg, tremor in neck, freezing, fatigue	Ropinirole, Stalevo, Amantadine, Clonazepam	Deep vein thrombosis left leg 2010	
P61	248	2	Bilateral tremor in arms	Carbidopa, Pramepexole,	Hypothyroid	Levathyroxine
P63	148	3	Bilateral tremor arms and legs, fatigue	Apo-go pen, Baclofen, Co-careldopa,	Diabetes (type 2)	
P64	33	2	Bilateral arms and legs, impaired gait and balance, falls, fatigue	Madopar, Sinemet	Congenital heart palpitations	
mean	108.8					
stdev	61.8					

**PADLS scores range from 1-5 where 1 = no abnormality and 5 = housebound (see appendix 10)*

3.4.5 Sample Size

A group of 43 participants were recruited of varying levels of severity of dysarthria.

Calculating Power

It is important to determine an appropriate sample size when investigating the effect of an experiment because too small a sample increases the likelihood of making a type 1 error (failing to detect a real difference between groups) whereas too large a sample is wasteful of resources and may result in detecting a difference at a given level of α which is of little practical or clinical importance. Calculations were therefore carried out to determine the number of participants necessary to achieve a suitable level of statistical power. The power of a statistical testing procedure is the ability of the procedure to detect a difference between groups at the given α-level. Cohen (1988) recommends a power level of .8 (i.e. an 80% chance of detecting a genuine difference). There are very few studies which provide comparison data between people with motor speech disorders and neurologically normal people on measures of social communication or social anxiety and which can indicate a likely effect size when investigating such variables. A study that does is Donovan (2005) in which the effect size (Cohen's d = 1.9 r=.69) exceeds Cohen's threshold for a 'large' effect size. For a power level of .8, α-level of p=.05, an effect size of this magnitude indicates an appropriate sample size of 25 which this investigation exceeds (Donovan, 2005).

3.4.6 Ethical Considerations

Approval for the investigation was granted by the DMU Faculty of Health and Life Sciences Research Ethics Committee in October 2007 (appendix 3)

Main ethical issues identified were:

- ensuring that participants' consent to participate, including being recorded, was fully informed, including provision of details on the aims of the study, requirements on participants and right to withdraw;
- maintaining confidentiality of participant data including arrangements for security of information;
- risk that participants become more aware of speech impairments.

Risks relating to each of these issues were identified and procedures put in place to manage the risk to the satisfaction of the Research Ethics Committee of the Faculty of Health and Life Sciences. Prospective participants were informed about the existence of the study either by a presentation to a local branch of the support group or through their newsletter. It was emphasised that participation was voluntary and people were asked to register their initial interest by providing their contact details. An information sheet was provided on which to base their decision to proceed (appendices 2.1 and 2.2). This outlined the purpose and nature of the study and the data collection tasks, provided information about the researchers, emphasised the right of withdrawal, described the measures taken to protect confidentiality, described how the results would be treated and disseminated and described the process available

to the participant should he/she have any complaint about the way that they were treated. In order to avoid any situational pressure to take part a period of at least forty-eight hours was allowed following a verbal presentation before the researcher contacted prospective participants again individually to answer any questions and to establish whether they wished to take part. Participants were also given an opportunity to ask any further questions before data collection started. When they were satisfied that they were fully informed, all participants were required to sign a consent form (appendix 6) confirming this and consenting to being recorded on video audio and a copy of this form was provided to them. Where participants were notified of the project through a newsletter and made contact with the researcher the information and consent forms were sent to them by post with a covering letter (appendix 7).

4 Chapter 4 Quantitative Measures

4.1 Non-speech Measures

A range of non-speech measures were taken including cognition, depression, anxiety and apathy, all of which might affect the extent and manner in which people engage socially. It should be noted that the aim of the project was not to explore the influence of all these variables as factors affecting social life. This would have been beyond the resources of the project and would have required recruitment of a very large sample in order to make statistical analysis of all factors meaningful. Therefore, the purpose of including these measures was to exclude participants outside normal limits on each measure (excepting the measure of activity in daily living), and to control for variation within the normal range when comparing groups, in order that the effect of dysarthria on social life could be examined more specifically. These considerations played a part in selecting the measures used rather than others which might be considered useful for grading extent of impairment or diagnosing type of disorder.

4.1.1 Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975) (Appendix 9)

Rationale for Inclusion

The SPMSQ (Pfeiffer, 1975) is a screening assessment of cognitive ability which has been validated for use in detecting impairment in memory, confusion and dementia (Welch and West, 1999; Eissa et al., 2003; Erkinjuntti et al., 1987). As cognitive impairment is associated with Parkinson's disease it is important to detect it in potential participants. Cognitive impairment may be a factor in changes in social participation and was also likely to affect completion

of a number of tasks in this study. It was chosen in preference to alternatives such as the Mini-Mental State Examination (Folstein et al., 1975) and the Addenbrookes Cognitive Examination (Mioshi et al., 2006) because it offered the most time-economic means to achieve the objective of identifying participants who met inclusion criteria of normal cognitive functioning. Identifying degree or type of cognitive impairment was not a necessary goal as it was beyond the scope of the project to factor in all impairment variables that might affect social functioning. A measure of cognition designed specifically for use with people with PD, the Parkinson Neuropsychometric Dementia Assessment (PANDA) (Kalbe et al., 2008) may offer greater sensitivity for this sample but was not available before data collection was substantially completed. A key feature of the PANDA's design suitability for PD was the incorporation of a measure of depression. In this study depression was screened separately (see below).

Properties

The SPMSQ addresses a range of intellectual functions: short and long term memory, orientation, information about current events, serial mathematical tasks. It is short and easily scored, sensitive to the full range of cognitive functioning and suitable for community dwelling populations, taking into consideration educational level. Items within the SPMSQ which test orientation and memory based on participant report (e.g. mother's maiden name) were corroborated using other data sources such as partner or family member. The SPMSQ is a stable measure. Test retest correlations of .82 and .83 were

recorded for two groups tested at four week intervals. Content of the test was derived from current clinical practice and from existing tests of cognitive ability such as the Wechsler Memory Scale (Wechsler, 1945). Concurrent validity was established using two group comparisons of SPMSQ scores with diagnosis of organic impairment.

Type of Data Yielded

The SPMSQ yields data which can be treated as interval. The questionnaire consists of ten questions providing a score between 0 and 10. The threshold for adequate cognition is a score of 8. Therefore all participants were required to achieve a threshold score of 8 on this scale for inclusion in the study.

4.1.2 The Parkinson's Disease Activities of Daily Living Scale (PADLS) (Hobson et al., 2001) (See Appendix 10)

Rationale for Inclusion

The PADLS (Hobson et al., 2001) is a self-report measure of functional mobility which assesses general motor performance through such daily functions as dressing, washing, housework, walking and driving and which requires the participant to consider the effects of medication on physical mobility. It is therefore helpful for use as an inclusion/exclusion measure in integrating motor impairment and medication effect in an evaluation of impact on daily life using a single global rating which has higher face validity in relation to social activity than a scale of the severity of motor involvement alone such as the Hoehn and Yahr scale (Hoehn and Yahr, 1967). Although the PADLS does not index progression of disease, as the Hoehn and Yahr scale is frequently used to do, it

correlates positively with the Webster scale of severity in Parksinson's disease. This assessment is included as it is possible that physical mobility, especially as it applies to everyday functioning, may have influenced social participation. Changes in mobility may occur in PD but the PADLS is a self-report instrument and so the data gathered were contemporaneous with all other assessments and data gathering for this project, which is an important advantage when considering inclusion and exclusion criteria. Assessments of motor performance such as section 3 of the UPRDS (Goetz et al., 2008) would provide greater detail. However, the primary researcher lacked suitable qualification or experience to administer this and test results obtained from other sources would perforce have been gathered at an earlier time when participants' mobility may have differed.

Properties

The PADLS is a valid and reliable assessment. Initial face validation was carried out with patients who had Parkinson's disease, carers and Parkinson's disease specialists. Construct validity was established using the established Webster Scale of severity in Parkinson's disease which correlated positively with PADLS scores ($r=.64$, $p<.001$). Retest reliability with a clinical Parkinson's population by the authors was good ($r= .89$, $p<.0001$) (Hobson et al., 2001).

Type of Data Yielded

The PADLS provides ordinal data consisting of a five point rating scale yielding a score between 1 and 5. 1 indicates no difficulties and 5 indicates extreme

difficulties including being unable to leave the home independently. Examples of expected difficulties are provided for each level. Participants with PD were required to score between 1 and 4.

4.1.3 The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) (see appendix 11)

Rationale for inclusion

HADS (Zigmond and Snaith, 1983) was developed to detect anxiety and depression in non-psychiatric in-patients. It has been judged effective in detecting the presence and severity of anxiety and depression in a range of patient groups and in the general population (Crawford, Henry, Crombie, & Taylor, 2001). It is a 14 item self-report questionnaire consisting of 7 items designed to identify and measure anxiety and 7 items designed to identify and measure depression. Depression is common among people with PD with prevalence estimated at 20-45%, lower prevalence generally being reported in community studies (Rickards, 2005). As the effects of depression include lower levels of social activity it was important to screen participants for the presence of depression.

Properties

The psychometric properties of the scale have been reviewed thoroughly by (Bjelland, Dahl, Haug, & Neckelmann, 2002) from which the following findings are taken. Cronbach's alpha for internal consistency in fifteen studies varied from .67 to .90. Concurrent validity for the HADS depression sub-scale is reported as very good as measured by correlation with the Beck Depression

Inventory, the Montgomery Asberg Rating Scale and the General Health Questionnaire (range .50-.81).

Type of Data Yielded

The HADS provides data which may be treated as interval data and generates a score between 0 and 21 for anxiety and a score between 0 and 21 for depression. A score of 0-7 indicates normal, 8-10 mild, 11-15 moderate and 16-21 severe depression. Participants were required to score between 0 and 7 for inclusion in the study.

4.1.4 Lille Apathy Rating Scale (LARS) (Sockheel et al., 2006)(Appendix 8)

Rationale for Inclusion

Apathy is characterised by behavioural symptoms which include reduced interest in, engagement in and initiation of activities in daily life and is commonly caused by frontal lobe dysfunction (Dujardin et al., 2007). In Parkinson's disease, subcortical-frontal circuits are involved due to basal ganglia dysfunction and so apathy is a frequently observed symptom with estimates of prevalence of at least 16.5% (Aarsland et al., 1999). Apathy is not associated with severity of motor symptoms or depression but is more frequent where cognition is impaired (Dujardin et al., 2007). Apathy can be measured using the Lille Apathy rating Scale (LARS) (Sockheel et al., 2006). An advantage of this

scale is that it contains a new dimension of self/social awareness which corresponds to social apathy as designated by Stuss et al. (2000).

Properties

The LARS is a standardised interview with 33 items organised into nine clinical domains of apathy. It has been validated on a group of 159 Parkinson's disease patients (Sockheel et al., 2006). Content validity derives from the inclusion of the main clinical features of apathy following a survey of the literature. These include lack of interest, lack of initiative, extinction of novelty seeking and motivation, blunting of emotional responses, lack of concern, poor social life and self and social awareness. Principal components analysis by the authors shows four primary factors represent distinct dimensions of apathy: intellectual curiosity, self-awareness, emotional blunting and action initiation.

In their study, Sockheel et al (2006), using Cronbach's alpha, found internal consistency between items and between sub-scales results were high (.80 and .78) and spilt half reliability reached .84. Test retest reliability for a group of 35 patients was .95.

Type of Data Yielded

The LARS yields data that can be treated as if it were interval data. Items 1-4 of the LARS are scored on a five point scale (2, 1, 0, -1, -2). Items 5-33 are scored on a three point scale (1, 0 or -1). The total score may vary between 36 and -36. Higher levels of apathy are indicated by higher scores. The scale classifies

results into non-apathetic (-36 to -22), mildly apathetic (-21 to -17), moderately apathetic (-16 to -10), severely apathetic (-9 to 36). Participants were interviewed using the LARS and only those scoring -36 to -22 were included in the study.

4.2 Speech Measures

4.2.1 Sentence Intelligibility

Rationale for Inclusion

Although there is no consensus yet surrounding which, if any, measures address the impact of speech impairment (Sussman and Tjaden, 2012) measures of intelligibility would appear to be a reasonable choice . Of the various options available it was necessary to make decisions regarding the advantages and disadvantages of their characteristics.

It was decided that item identification offered more advantages overall than scaling estimations of intelligibility. In scaling techniques, listeners rate speakers' overall intelligibility. Those which ask the listener to estimate the global intelligibility of the speaker using an equal appearing interval scale such as that used in the UPDRS (Zraick et al., 2003) have been criticised in terms of their validity and accuracy (Schiavetti, 1992) and listener ratings have wide dispersion (Yorkston and Beukelman, 1978). Scales which use direct magnitude estimation, especially where a modulus is used, ensure that listeners compare using a fixed reference but variations in the characteristics of the modulus

produce large differences in the estimations given rendering comparisons between studies problematic (Kent and Kim, 2011). For these reasons item identification was a preferred method.

Item identification by transcription may be based on recovery of words, sentences, passages or conversational speech. Although conversation has the highest ecological validity, free and even guided conversation presents great difficulties in identifying the extent of loss of intelligibility and in making comparisons between speakers. Monologues and reading passages offer greater standardisation of material for analysis and speaker comparison but the effects of listener familiarity must be controlled for. For these reasons transcription of words or sentences was deemed preferable.

In transcription tasks listener responses may be in either closed format (e,g, multiple choice) or open format where the listener transcribes without textual options. For single word identification, closed format response is standard and this results in higher intelligibility scores (Vigouroux and Miller, 2006; Yorkston and Beukelman, 1978). As many of the speakers in this study were only mildly dysarthric single word intelligibility scores were therefore likely to be close to or at ceiling levels and consequently less helpful in discriminating between participants.

Finally, speech rate can also affect intelligibility. Intelligibility can be increased by decreasing speaking rate as has been found in ataxic and hypokinetic dysarthric speakers (Yorkston et al., 1990). This can mean that although

underlying speech impairment may be quite marked, transcribed intelligibility scores fail to indicate this (Sussman and Tjaden, 2012). To address this use of compensatory rate reduction to increase intelligibility Yorkston and Beukelman (1981) proposed incorporating speaking rate with percentage transcribed intelligibility scores to produce a 'communication efficiency ratio' (CER). This measure captures both speaking rate and intelligibility such that high intelligibility accompanied by low speaking rate results in a low CER. However, although CER has been used in a number of studies including some with participants with PD (Murdoch, 2011; Constantinescu et al., 2011; Farrell et al., 2005) there are some objections to its use particularly with speakers with hypokinetic dysarthria. Kent et al. (1989) questioned the underlying construct of communication efficiency as there is no independent demonstration of a relationship between rate of speech and efficiency of communication, only percentage of accurately transcribed words. Kent et al. (1989) also pointed out that the validity of CER for speakers with more competent speech, i.e. mildly dysarthric, is also questionable. The CER's value rests on the assumption that increased speech rate means greater efficiency but this is not always true. In the case of speakers with PD faster than normal speech rate may be part of the presenting symptoms and can contribute to loss of intelligibility but would be represented by CER as a benefit. CER may be useful as a measure for populations with more homogenous speaking rates than those with PD.

It was therefore decided that sentence transcription offered the greatest advantages as a measure of intelligibility. Assessment of sentence intelligibility

was taken from the Assessment of Intelligibility of Dysarthric Speech (Yorkston and Beukelman, 1981). At the same time it is recognised by the researcher that this form of assessment has certain limitations and may not fully reflect the severity of the underlying speech impairment (Sussman and Tjaden, 2012).

Properties

The assessment has been extensively used in research and has excellent face validity. It is designed to avoid listener familiarity with speaker and material, both of which are associated with variation in intelligibility rating (Yorkston and Beukelman, 1978) and to avoid dispersion of scores typically associated with estimates of intelligibility (Yorkston and Beukelman, 1980). Reliability is very good: inter-judge reliability is very high (group means r=.97-.99) and intra-judge reliability for different sentences but the same speaker r=.96-.99.

Type of Data Yielded

The task required the speaker to read aloud 22 sentences of between 5 and 15 words, randomly selected from a pool of 1100. These were recorded and transcribed by a naïve listener. The number of accurately transcribed words was counted and converted into a percentage intelligibility score. Recordings were exported into a software audio editing application, Audacity, (Mazzoni and Dannenberg, 2006) for playback through a Toshiba Satellite-Pro laptop computer.

Transcriptions of recordings for intelligibility ratings were carried out by an additional naive listener and inter-judge reliability was investigated using correlational analysis. Inter-judge reliability was very high (r = .97) and so intelligibility scores from both judges were averaged to produce the final intelligibility scores.

4.2.2 Frenchay Dysarthria Assessment (FDA) Enderby (1983) (Enderby and Palmer, 2008) (see appendix 12)

Rationale for Inclusion

This assessment was included in order to provide a measure of the severity of motor impairment. The FDA (Enderby, 1983) is a standardised assessment of motor speech for diagnosis of dysarthria which is sensitive to change, is reliable and clinically useful. It is in common use clinically and in research work although as its focus is on accuracy of oromotor and speech related movements the assessment does not report on impact of dysarthria. Measures of intelligibility arguably are more informative regarding impact as they are the result of combinations of relevant dimensions: underlying speech impairment, speaker compensation, listener and environmental characteristics. However, as discussed above, intelligibility is not strongly related to psychosocial variables in dysarthria. Speakers with dysarthria are highly sensitive to changes in their speech which may not affect intelligibility significantly but which they attribute as causes of behavioural change in social situations (Miller et al., 2006). It is possible that, in relation to social presentation, underlying oromotor impairments are more salient to speakers than are intelligibility scores, which

focus on the impact on the listener and which partly reflect non-speaker variables.

Analysis was completed using the modifications introduced in the second edition (P Enderby & Palmer, 2008) which improved the reliability of descriptors. A 19-item version of the assessment was used following Hill et al. (2006) excluding certain items: those which assess swallow function were not included in the analysis because these are self-reported and cannot be checked for reliability and tongue at rest and palate maintenance were also excluded because they could not be clearly observed on video for reliability checking. The assessment of intelligibility was not included because more robust measures for intelligibility were already included in the protocol (see above section 4.2.1). Video recordings of a sample (n = 4) of the assessments were rated by a second clinician experienced in working with people with motor speech impairments. Inter-judge reliability was high (*r =.84)*

Properties

The FDA has clear face validity. It is divided into sections determined by motor speech sub-systems: respiratory function, lip movements, jaw movements, palate movements, laryngeal function, tongue movements and intelligibility. Each section includes non-speech and speech tasks. A 9 point scale from normal to no function is applied with descriptors provided for grading. The assessment is easy to use and inter-judge reliability is high (r=.79 - .92). It has been used extensively in clinical and research settings. Concurrent validity was

established through testing on patients with known/diagnosed aetiologies. Discriminant analysis confirms 90.6% of cases were correctly classified by the FDA. A blind analysis of FDA results for a sample of 112 patients returned an accurate diagnosis of dysarthria type in 89.3% of cases (Enderby 1983).

The relationship between impairment to oromotor movement and speech impairment has been challenged (Ziegler, 2003; Weismer, 2006) as there are reasons to believe that control of oromotor movement and speech are task specific. The FDA uses a mix of tasks employing both non-speech and speech movements. Therefore any interpretation of results arising from use of the test must be cautious about the extent to which the FDA indexes severity of speech impairment per se as well as impairment of oromotor movement. Non-speech and speech items within the FDA were compared using Pearson's correlation (r = .77, p *<.001)* which indicates that both sets of scores were measuring a single underlying dimension.

Type of Data Yielded

The FDA uses a 9 point scale for each of 25 tasks involving the motor speech structures. Tasks are divided into subsets: reflex, respiration, lips, jaw, palate, tongue, laryngeal and respiratory, each of which may yield a mean between 1 and 9. Average scores for each participant were calculated. While equal appearing interval scales are problematic for prothetic dimensions such as intelligibility where the dimension is additive in nature, this is not the case for

metathetic or non-additive dimensions, such as volume or range of movement, which underly the items in the FDA (Kent and Kim, 2011).

4.3 Social Participation

4.3.1 Social Activity Checklist (SOCACT) (Cruice, 2001)(Appendix 13)

Rationale for inclusion

While people with Parkinson's disease have reported their evaluations of their own effectiveness in some communicative situations (Donovan, 2005) and on their responses to communication changes (Miller et al., 2006; Walshe and Miller, 2011), there has been so far no attempt to quantify social activity levels. The Social Activity Checklist (SOCACT) (Cruice, 2001) provides a structure for doing this. Originally designed for use in documenting the social activity of a group of people with aphasia, it is not a measure which is limited in application to people with aphasia or any communication-impaired populations. Indeed Item selection is based on research from stroke, gerontology and mental health populations. Its purpose is to provide a basis for recording type and frequency of social activities and is independent of underlying pathology. The SOCACT is not an assessment of communicative participation and does not gather data on specific communicative activities or rate communicative success in social situations. Rather, it records range and frequency of activity. Obstacles to engaging in those activities may arise from difficulties with communication, with mobility or with other aspects of PD and are explored qualitatively in section 7.

Properties

The SOCACT is a checklist which collects data on the range of social activities undertaken. It has twenty categories of activity which can be used to prompt the participant to report all activities they are involved in. Among the twenty categories there are three sub-categories of activity: leisure, informal groupings (e.g. family gatherings) and formal groupings (e.g. classes). Frequency of the activity is recorded (>weekly, weekly, fortnightly, monthly, <monthly) which permits a more detailed view of pattern and overall level of activity. This allows the researcher to measure the volume of group associations of both formal and informal types which are central to concepts of social participation (Guilen et al., 2011; Paxton, 1999).

Type of data yielded

An overall score is obtained which is a tally of all the activities in which the participant is involved. In addition, tally of activities within sub-categories was obtained. Data were collected recording the frequency with which each activity was carried out. Activities were assigned by participants to one of five categories: more than once per week, weekly, fortnightly, monthly, less than monthly. From these data a cumulative monthly figure for activity was calculated for each participant using the following algorithm: (monthly activity x 1) + (fortnightly activity x 2) + (weekly activity x 4) + (>weekly activity x 8). For activity categorised as >weekly a conservative estimate of 2 x per week per activity (and therefore 8 x per month) was used as this was the minimum number indicated by participants and avoided inflating frequency of activity. From this figure an indication of total monthly activity was obtained which took

account of differences between participants in terms of the frequency of their activities.

4.3.2 Social Network Analysis (Antonucci and Akiyama, 1987)(Appendix 14)

Rationale for Inclusion

Social network analysis provides a view of the extent and nature of the social contacts which a person makes over different periods of time. The information that a network description provides may be structural e.g. whether the social contact is a spouse, sibling, friend etc. and functional i.e. the type of social support that it provides. A convoy model as proposed by (Antonucci and Akiyama, 1987) provides additionally a view of the network which reflects the changes in roles that members of the network may play over time. For example, the supportive roles which are provided by children and friends may vary at different stages of life as circumstances affect the capacity to provide support by either child or friend. The convoy model establishes the importance of a relationship to the participant as well as the structural and functional characteristics of the relationship by recording the centrality of a relationship to the person at that particular time, allocating the network member to either an inner, middle or outer circle.

Social network size does not capture the full range of resource that is available to an individual from that network. Other factors are the number of people willing to support the individual, the resources that are available to them and the extent to which members of the network are willing to support the individual

(Tijhuis et al., 1998). It was not within the scope of this project to collect such data but to begin by examining basic network variables because number of social contacts, alongside number of group associations, is held to be a key indicator of social participation (Guileen et al., 2011; Paxton, 1999). Kahn and Antonucci (1981) predict that in chronic disease different sections of the network will remain stable as others change. It would be anticipated that during chronic illness those closer to the individual at focus and those with longer-standing connections i.e. family, are more likely to remain. Therefore data were gathered for each circle of the network and also for the types of relationships that the participants had with the members of the network to explore any effects that dysarthria in PD might have.

Properties

As one measure of social participation, social networks have face validity. Social networks clearly reflect social participation and so in order to address the research questions of this study a description of participants' social networks was required. However, it is acknowledged that social participation is not defined by social network size or characteristics alone and will provide only one perspective on this dimension. Hence, data on volume of social activity of different types was collected (see 4.3.1 above). In addition, as purely quantitative measures of activity and network are not informative about qualitative aspects of the interactions which occur during social participation, levels of anxiety associated with different situations and levels of avoidance were included (4.3.3 below)

Type of Data Yielded

The networks yielded interval data in the form of numbers of individuals within the social network: overall membership of the network, numbers of contacts in each of three categories (inner, middle and outer circle) reflecting centrality of the relationship to the participant. The allocation of members of the network to circles was done by the participants using standard descriptions (Antonnucci and Akiyama, 1987, see appendix 14) given to them by the researcher. In addition, participants were asked to indicate which of four relationships the network member had to them: close family (partner, parent, child, sibling), other relative, friend, other contact.

4.3.3 Inventory of Interpersonal Situations (IIS) (Van Dem-Baggen and Kraaimaat, 1999) (Appendix 15)

Rationale for Inclusion

Social participation may be quantitatively indexed using volume and frequency of social activity, group association and social network size and characteristics (Guilen et al., 2011). However, motivation to participate may be influenced by a range of factors which then impact on extent of participation. Key factors associated with PD (cognition, depression, anxiety, apathy, mobility) have been controlled within the study, however, factors which are associated with communication impairment as well as underlying pathology are a subject of investigation. People with dysarthria have described various factors which negatively impact the quality of interactions (Miller et al., 2006, 2008; Dickson et

al., 2008) and which increase the likelihood of avoidance of or withdrawal from social situations. In this study factors affecting change in social activity were investigated quantitatively using a measure of social anxiety (discomfort and avoidance), a dimension which has been shown to be affected in other communication-impaired groups (Kraaimaat, Van Dam-Baggen, & Vanryckeghem, 2002). The complex way in which factors contribute to social behaviour at an individual level was investigated qualitatively through in-depth interviewing (see section 6) and the ways in which these inform each other are discussed in section 8.

The Inventory of Interpersonal Situations (Van dem-Baggen and Kraaimaat, 1999b) is a self-report questionnaire which assesses emotional and behavioural aspects of social anxiety. Social anxiety refers to subjective distress experienced in social situations and lack of assertiveness in social behaviour and is distinct from social phobia. It has both cognitive and behavioural aspects which are distinct from each other (Van Dem-Baggen, Kraaimaat, & Elal, 2003). There is evidence that people with dysarthria in PD may experience social anxiety (Kummer et al., 2008; Ellgring et al., 1993) and this has been shown to be the case in other groups with chronic speech production impairments where speaking is thought to be associated with anticipation of social harm (Kraimaat et al., 2002; Messenger et al., 2004). There are a number of instruments for measuring anxiety with applicability to social situations but these have disadvantages for the current study. The Fear of Negative Evaluation scale (Watson and Friend, 1969) is not sufficiently specific to social anxiety and does

not measure avoidance of situations. The Social Avoidance and Distress scale (Watson and Friend, 1969) includes items designed to identify both discomfort in and avoidance of social situations but the overall score does not allow these two dimensions to be differentiated. The Liebowitz Social Anxiety Scale (Liebowitz, 1987) has both anxiety and avoidance scales but lacks the range of situational sub-categories present in the Inventory of Interpersonal Situations (IIS). Overall, therefore the IIS offered the most advantages for measuring social anxiety in this, speech-impaired sample. The IIS supplemented the social network and social activity data by recording the subjective discomfort that participants experience in a range of social situations and by documenting the extent to which they avoid these social situations, aspects of social lives which would not be identified by network and activity levels alone.

Properties

The authors have established that the IIS has good internal consistency, content validity, criterion validity and construct validity, is stable and sensitive to change over time (Van dem Baggen and Kraimaat, 1999). Content is derived from a large pool of items found in other tests of social anxiety and from clinical practice. Two scales were developed, one for discomfort and one for frequency. These were tested for discriminant validity and ambiguity leaving 35 items in the final scale.

Concurrent validity was assessed using a normal group (n=276), a socially anxious group (n=217) and a general psychiatric group (n=363) and convergent

validity was established by positive associations of the discomfort scale with other measures of social anxiety. Discriminant and predictive validity were also established in development of the scale. The IIS is stable over time, has good internal consistency and is sensitive to change over time.

The IIS is divided into five sub-scales allowing comparison of different types of situation for both level of anxiety and avoidance:

- Giving criticism
- Giving an opinion
- Giving a compliment
- Intitiating a social contact
- Making a positive self-statement

Type of Data Yielded

The IIS contains 35 situations which participants rate for discomfort and frequency of avoidance on a scale from 1-5 in two response sets. A score between 35 and 175 is generated for both discomfort (IIS-D) and frequency (IIS-F). Because of the wording of the scales high social situational distress results in a high score on the discomfort scale and high avoidance of social situations results in a low score on the frequency scale. Both discomfort scores and frequency scores were recorded for all participants.

4.3.4 Summary

Social participation was investigated quantitatively using measures of social activity and social network, sub-categorised to allow investigation of

components of participation and also characteristics of network composition relevant to change in chronic disease. Social anxiety, an affective and behavioural measure relevant to communication change, was also investigated. The limitations of quantitative measures in displaying how speech and other variables present in the individual with PD interact is acknowledged and addressed through the use of qualitative interview data supplementing the quantitative data within the study.

4.4 Equipment

4.4.1 Hardware

Audio recordings were made using a Marantz PMD670 solid state digital recorder with a sampling frequency of 44.1kHz and a recording bit rate of 128kbps, linked to a an AEG C 444L head mounted condenser microphone with 9volt power supply positioned a constant 2cm from the participant's mouth. The microphone is a pre-polarised condenser cardioid microphone with a frequency range of 20-20,000Hz.

Video recordings were made using a Panasonic HDS-SD1 digital video camera with a maximum data rate of 13Mb/s.

Recordings were stored on a Toshiba laptop computer and for intelligibility transcription were played back through Sony DR-220 headphones.

4.4.2 Software

Audio recordings were stored as .wav files for playback and analysis. Measurement of utterance duration was conducted using the Audacity audio editing application (Mazzoni and Dannenberg, 2006). The speech sound pressure signal was displayed at a magnification showing a scale at 1/100th of a second and readings were taken using the cursor function.

4.5 Data Collection Procedure

Participants were offered their own choice of location and all data was collected at the homes of participants. Timing of visits was arranged as convenient to participants with consideration for the optimum times within their medication cycle as appropriate.

Data collection for participants with PD was made in two visits not more than two weeks apart in order to avoid effects of fatigue.

Visit 1: obtaining consent, biographical and case history information, screening assessments (SPMSQ, HADS and Apathy Scale), dysarthria assessment and speech intelligibility (FDA, SIT).

Visit 2: social communication behaviour (social network analysis, IIS and interview).

Data collection for control participants was made during a single visit. All procedures were minimally invasive.

4.6 Matching Groups

4.6.1 Control and All PD Participants

In order to determine whether presence of and severity of dysarthria affected the dependent variables it was important to ensure that potential confounding variables were controlled for and to ensure that the groups being compared did not differ on dimensions that might have affected social functioning other than the presence and severity of dysarthria related to PD which was the focus of the study. The variables considered to be potentially confounding variables were age, gender, socioeconomic status and educational attainment as these are all factors which may influence social activity and participation in the general population. Other potentially confounding variables may arise from the presence of symptoms in PD other than dysarthria. Therefore, all participants were required to score within the normal range for cognition, apathy, depression and anxiety in order to ensure that the groups were comparable on these variables. Comparisons were also made between groups on these variables as, although all participants scored within the normal range on each variable, differences between groups would be informative in relation to the research questions.

In order to evaluate whether the groups differed on any of these variables comparisons were made between groups using appropriate statistical tests to

Table 4-1 Comparisons for age, gender, socioeconomic status and educational attainment (Control and PD groups)

Variable	Control	PD	Test /Result	*P value (2-tailed)*
	Mn sd	**Mn sd**	*t =.85(71)*	**.40**
Age	**70.9 9.5**	**69.1 8.1**		
	Frequencies			
Gender				
Male	20	28	Yates' χ^2 =.02 (1)	**.89**
Female	10	15		
Total	30	43		
Socio-economic classification				
A	0	0	Fisher's exact test	**.16**
B	0	1		
C1	12	12		
C2	**15**	**29**		
D	**3**	**1**		
E	**0**	**0**		
Total	30	43		
Education				
16	**11**	**18**	Fisher's exact test	**.35**
18	**10**	**14**		
Graduate	**5**	**10**		
Post-Graduate	**4**	**1**		
Total	30	43		

identify any statistically significant differences between groups. This is described below and data are summarised in table 4-1 and table 4-2. First the data for matching non-neurologically impaired participants with all participants with dysarthria and PD are presented. Then the division of the dysarthric speakers into two groups is described and following this the data for matching

the more severely dysarthric and less severely dysarthric speakers are presented.

Age

The mean age of the control group (n = 30) was slightly higher than that of the PD participants (see table 4-1). Standard deviations show that the dispersion of ages within each group was similar. Kolmogorov-Smirnov tests of data from both groups indicated that distribution was normal and a Levene's test indicated equality of variance between the two groups (see appendix 17). Therefore the data met assumptions for parametric testing and so a comparison of the means using an independent t test was carried out, $t = .85$ (df41), $p = .40$, 2-tailed) indicating that the control group and the group with Parkinson's disease did not differ significantly in terms of age.

Gender

Gender distribution of control participants and those with Parkinson's disease is shown in table 4-1. While the proportions of male and female participants differed very slightly in each group, a chi-squared test of the distribution yielded a p value of .89 (two-tailed) indicating that the difference was not statistically significant. The ratio of males with PD to females with PD in this study is 1.86 which falls within the range found by Wooten et al. (2004) (male: female = 0.88:1 – 2.04:1) and is very close to the figure found by Van den Eeden et al. (2003) (male:female = 1.91:1)

Socioeconomic status

Distribution of socioeconomic groupings (Market Research Society, 2006) is shown in table 4-1. A Fisher's exact test of this distribution showed no statistically significant relationship between diagnostic grouping and socioeconomic category (p = .16, 2-tailed).

It can be seen that the range of socioeconomic categories represented in both the PD and control groups is concentrated in the C1 and C2 categories and the sample is therefore not representative of either lowest or highest social groupings.

Education

Educational attainment was recorded in four categories: completed by age 16, completed by age 18, graduate (or professional qualifications gained post-18), post-graduate (including professional qualifications). The distributions are presented in table 4-1.

Although the control group contains a higher proportion of participants with education beyond the age of 18, a Fisher's exact test of the distribution returned a significance level of p = .35 (2-tailed) indicating no statistically significant relationship between group and educational attainment.

It can be seen from the table that the number of participants completing their education at 18 is 33% of PD group and 33% of controls during a period when

the number of people in school and aged 17 was 10% (in 1953) and 18% (in 1970). It is likely therefore that the sample contains a high proportion of people educated beyond 16 when compared to the population as a whole. It can also be seen from the table that approximately 30% of control participants and 26% of participants with PD completed their education to graduate level or above. In the period when most of the participants would potentially be graduating (taking 1 sd either side of the mean = c1952-1970) graduates as a proportion of school leavers were 3.4% and 8.4% (Bolton, 2012), therefore the sample is not likely to be representative of the educational attainment of population as a whole within the age range of the participants.

All participants were screened for level of cognitive functioning, apathy and depression and all participants met the inclusion criteria, i.e. to score within normal limits on these measures. However, as cognitive impairment, higher levels of apathy and higher levels of depression are associated with Parkinson's disease it may be expected that the participants with Parkinson's disease score differently on these measures within the range of normal performance. The results in Table 4-2 show that for these measures, although within normal limits, the participants with Parkinson's disease demonstrated lower cognitive functioning (non-significant), higher levels of apathy, higher levels of anxiety and higher levels of depression which were statistically significant

Table 4-2 Comparisons for cognition, apathy, depression and anxiety (Control, PD)

	Control		All PD		Degrees of freedom = 41, n = 43					
	mean	*sd*	*mean*	*sd*		*test*	*t val.*	*z score*	*p*	*tail*
Cognition[1]	9.7	0.6	9.3	0.8		*U**		-.10	.16	*1*
Apathy[2]	-28.8	2.9	-26.7	3.6		*t***	-2.53		.005	*1*
Anxiety[3]	4.77	2.7	6.88	3.9		*t*	-2.57		.005	*1*
Depression[3]	2.2	1.6	4.2	1.9		*U*		-4.4	<.001	*1*

[1]SPMSQ Short Portable Mental Status Questionnaire
[2]LARS Lille Apathy Rating Scale
[3]HADS Hospital Anxiety and Depression Scale
*Mann-Whitney used where data are not normally-distributed
**equal variances not assumed
.

Summary

On demographic measures relevant to social functioning which might have been confounding variables (age, gender, socioeconomic status and education) the participants with PD in this study were not differentiated from neurologically unimpaired control participants. Therefore, when comparing results for these two groups on the dependent variables social network, activity, anxiety and avoidance, such group comparisons are more likely to be able to meaningfully distinguish any effects due to presence of dysarthria related to PD. On cognitive and affective measures, although scoring within normal limits, the participants with Parkinson's disease were differentiated from neurologically unimpaired participants on some variables. For these measures, both the overall level of performance of the participants and these observed differences will be considered in the discussion of the results below.

4.6.2 Severity of Dysarthria

In order to test the hypothesis that severity of dysarthria impacts social variables negatively it was necessary to divide the dysarthric speakers into more severely and less severely impaired groups. 'There is no standard measure of speech severity in dysarthria' (Kim et al., 2011, p417). There are several measures which may be considered for this and these were evaluated prior to deciding which measure was most suitable: motor speech assessment; sentence intelligibility or communication efficiency ratio.

Sentence intelligibility is frequently used to index severity of dysarthria although it measures impact on the listener rather than severity of underlying speech impairment in dysarthria. There are some shortcomings associated with this measure and these were discussed in section 4.2.2 above. In addition, transcribed sentence intelligibility is affected by a number of factors including both the underlying impairment of speech production and the speaker's compensatory behaviour. For example, reducing speech rate typically increases intelligibility in dysarthric speakers (Yorkston et al., 1990). The result of such compensatory behaviour, which may be taught or developed spontaneously by the speaker, is to increase intelligibility. This is a desirable goal and one, therefore, speakers are likely to adopt and so intelligibility and impairment do not necessarily have a linear relationship. Study of the data for this sample revealed that scores for sentence intelligibility were relatively narrowly dispersed and concentrated in the upper decile of the scale between the 90% and 100% intelligibility points. This can be seen in Figure 4-1

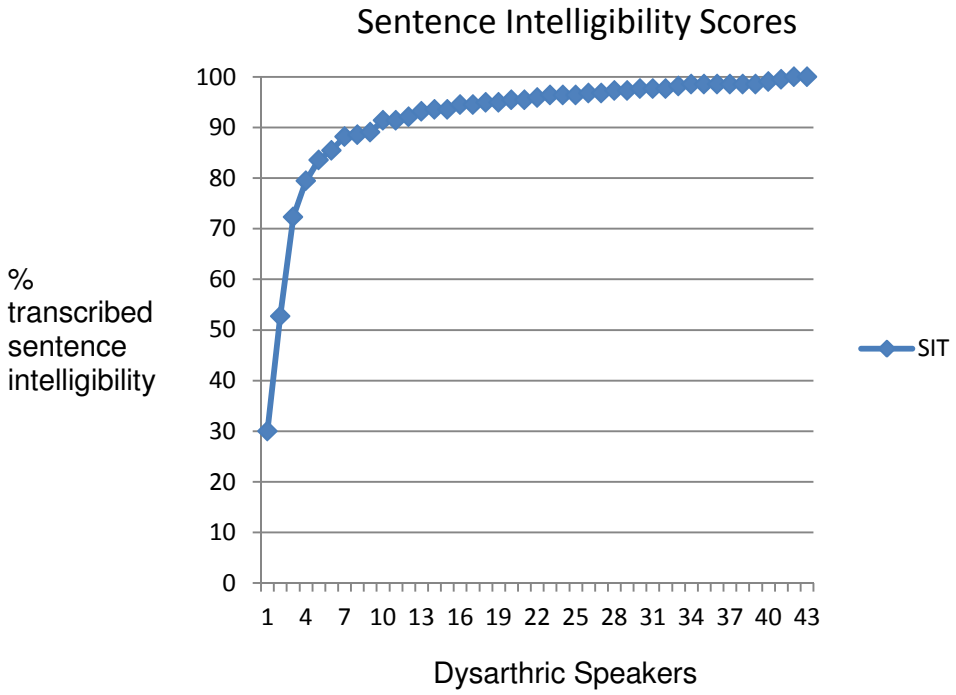


Figure 4-1 Distribution of sentence intelligibility scores

The result of using a narrow set of intelligibility scores may further render distinctions between upper and lower levels of severity of dysarthria difficult to discern as they are concentrated in the mild end of the spectrum. Earlier studies have indicated that intelligibility does not have a clear relationship with social and psychological variables in dysarthric speakers (Miller et al., 2008; Walshe et al., 2008) and that intelligibility is not closely related to speech impairment (Sussman and Tjaden, 2012). Where impact on social variables is concerned, the speaker's awareness of changes to their speech may have an important role, affecting their confidence in social situations even where intelligibility is good. Intelligibilty scores were obtained in optimal conditions and may therefore exaggerate communicative performance (Hartelius and Miller, 2011). Therefore,

this range of intelligibility scores may mask a greater range of underlying impairment in the sample.

A means of adjusting for speech rate which may be contributing to higher intelligibility is to use the communication efficiency ratio (CER) (Yorkston and Beukelman, 1981). CER measures intelligibility but also combines this with the dysarthric speaker's speaking rate and with a speech rate norm to produce a value between 0 and 1.0 where 1.0 represents 100% intelligibility at normal speaking rate. However, the meaning of the fundamental construct of the CER, i.e. efficiency in communicating, has been challenged (Kent et al., 1989). The assumption that a slow speaking rate is a compensatory communication behaviour rather than a consequence of a medical condition is questionable and its application in speakers with PD in particular is problematic since speaking rate in dysarthria with PD has been shown to both decrease and increase in different speakers (De-Letter et al., 2006; Ludlow et al., 1987; Metter and Hanson, 1986). This makes it difficult to interpret the ratio derived in the CER because a speaker whose speech rate is increased as a result of their PD may be less intelligible to a listener, their speech may sound more unnatural to them and to listeners but their CER may return a 'normal' value. Study of the distribution of the CER scores for this sample showed that some speakers achieved a CER greater than 1.0 although they identified as having speech impairment (see Figure 4-2). It was therefore problematic to use CER scores as a measure of severity of dysarthria since the underlying speech impairment could not be indexed accurately.

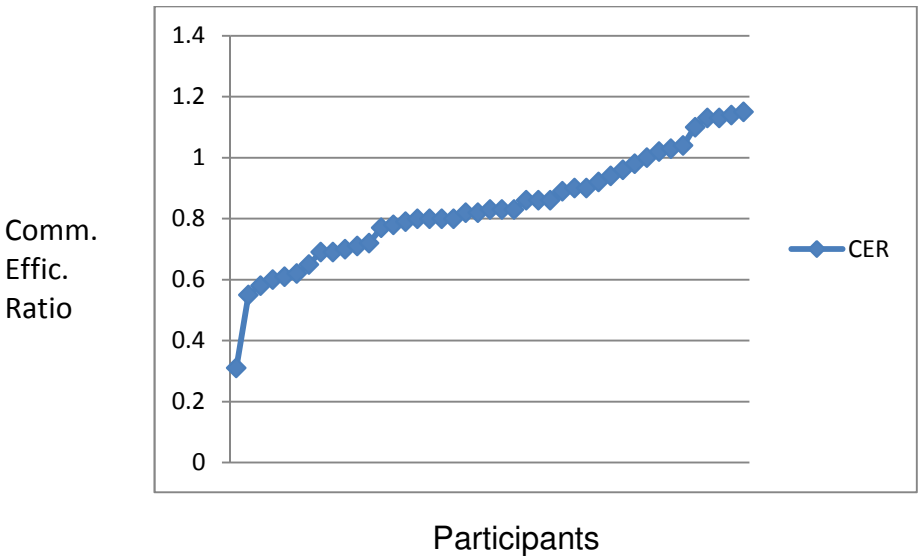


Figure 4-2 Distribution of CER scores

Data for the underlying motor speech impairment was collected from the participants based on their scores using the Frenchay Dysarthria Test (Enderby, 1983) modified in line with the second edition (Enderby and Palmer, 2008). This assessment requires the speaker to carry out a range of movements which test physiological functioning of components of the speech production system.

In comparison with the scores for transcribed sentence intelligibility, the underlying motor speech impairment scores are more evenly distributed across the range of possible values in the upper half of the scale, indicating that both mild and moderate dysarthria are present among this sample in equal numbers. SIT and FDA scores correlate positively but weakly (Spearman's $r = .31$) which further suggests that changes to underlying neural control for speech are not strongly related to intelligibility scores.

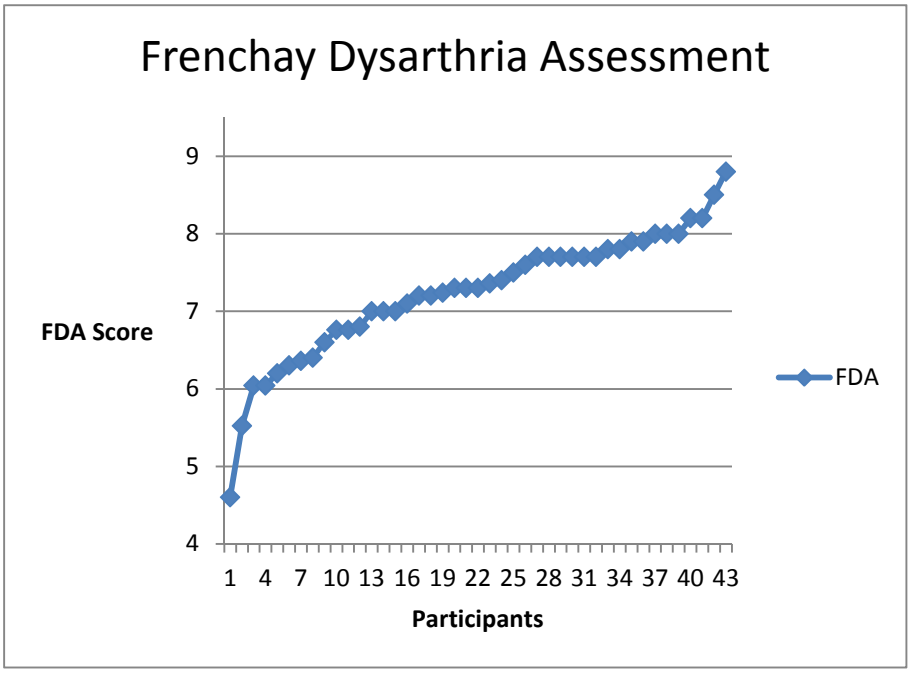


Figure 4-3 Distribution of scores for Frenchay Dysarthria Assessment

It is important to note that even changes to speech which do not register as any loss of intelligibility on assessment can impact speakers' attitudes to communicating in social situations (Walshe et al., 2008; Miller et al., 2008). Social participation was the focus of the current study and as an earlier analysis of a section of this sample using sentence intelligibility as the measure of dysarthria severity had not revealed an effect of dysarthria severity on social activity, network or anxiety (Brown et al., 2012, see appendix 21) it was therefore desirable when dividing the dysarthric speakers to consider using, in addition to a measure of intelligibility, another measure of dysarthria which indexed severity of underlying control of the speech production system as well.

It was decided to investigate the research hypotheses using scores from both sentence intelligibility and the FDA and to create two groups of more and less severely dysarthric speakers using a median split of those scores.

Summary

It is likely that some speakers in this study have compensated for their speech impairment by various means such as reducing rate with the effect of raising intelligibility towards the ceiling of 100%. For this sample, differences in intelligibility between speakers may be insufficient to detect differences among the group in social variables. Earlier research has shown both that intelligibility is not strongly related to psychosocial variables and that speakers are sensitive to changes in their speech even when intelligibility is 100%. For these reasons it was decided that investigation of the social variables under consideration here should be undertaken using motor speech impairment as the grouping variable (Frenchay Dysarthria Assessment) in addition to transcribed intelligibility.

4.6.3 Mild and Moderate Dysarthric Groups (Intelligibility)

In order to investigate the second hypothesis, that more severe levels of dysarthria will have greater impact on social variables than less severe dysarthria, the speakers with PD were first divided into two groups with higher and lower speech functioning using the scores from transcribed sentence intelligibility. Sentence intelligibility is considered to be an index of communication disability in dysarthria (e.g. Kent et al 1989) although recent research has brought into question the relationship of the measure to

psychosocial variables (Miller et al., 2006, 2008, 2011) and it is reasonable to suppose that differences in speech intelligibility in connected speech will impact on communication in social settings. It is possible therefore, that lower intelligibility may contribute to factors which influence uptake of opportunities for social communication within a social network and the level of social activity. It may also contribute to increased social anxiety and social avoidance. It was hypothesised that differences in sentence intelligibility would result in changes across the variables social network size, social activity, social anxiety and social avoidance. A median split was used to divide the PD speakers into a more intelligible (Mild, n = 22) and a less intelligible (Moderate, n = 21) group.

Mild and Moderate groups were compared on possible confounding variables both related to presence of PD (cognition, apathy, anxiety, depression, functional physical ability, duration of PD and duration of signs of dysarthria) and unrelated to presence of PD (age, gender, socioeconomic status and education). Results for PD-related possible confounding variables and for age are reported in Table 4-3.As it cannot be predicted whether differences between these groups on such variables will be directional the p values are reported as 2-tailed. Non-parametric Mann Whitney tests were used where data sets being compared did not meet parametric requirements (see appendix 16 tests of normality). The results show that there were no statistically significant differences between the groups on these variables, $p < .05$ in all cases. However, effect sizes for all variables except apathy and anxiety suggest that, to some degree, intelligibility scores index progression of aspects of PD other

than dysarthria. Age of onset may be significantly related to characteristics of PD. People with young onset of the disease have lower levels of depression, slower progression of disease and milder motor symptoms (Lewis et al 2005) and so differences in age of onset may influence social participation through action of these variables. Mean age of onset for these groups did not place either group

Table 4-3 Comparisons for age, cognition, apathy, anxiety, depression, mobility duration PD and duration speech signs (Mild and Moderate dysarthria) SIT

	Mild		Moderate		*test*	*t val.*	*z score*	*p (2 tail)*	*Effect size r*
	mean	*sd*	*mean*	*Sd*					
Cognition[1]	9.7	0.5	9.4	0.7	*U*		-1.23	.22	*.19*
Apathy[2]	-27.1	3.3	-26.4	4.0	*t*	-.64		.53	*.01*
Anxiety[3]	6.9	3.9	6.9	4.0	*U*	-.09		.39	*.01*
Depression[3]	3.7	1.8	4.8	1.8	*t*	-1.9		.07	*.28*
Mobility[4]	2.4	0.7	2.6	0.7	*U*		-1.25	.21	*.19*
Duration PD[5]	95.5	68.0	122.7`	52.5	*U*		-1.86	.06	*.28*
Age at onset (yr)	61.9	11.0	58.9	11.3	*t*	.90		.37	.14
Duration Speech[5]	64.7	68.9	58.9	49.5	*U*		-.146	.88	.22

[1]SPMSQ Short Portable Mental Status Questionnaire
[2]LARS Lille Apathy Rating Scale
[3]HADS Hospital Anxiety and Depression Scale
[4]PADLS Parkinson's Disease Activities of Daily Living Scale
[5]Duration in completed months

within Lewis et al's 'young onset' group (mean age at onset 50, sd 10 years) as can be seen in Table 4-3 above. There was no significant difference between these means, $t(41) = .90$, $p = .37$ (2 tailed) and so young onset characteristics are not likely to have influenced behaviour of either group.

Comparisons between Mild and Moderate groups (Sentence Intelligibility) were also carried out for gender, socioeconomic status and education. Frequency data are presented in Table 4-4 with chi-squared results (or with Fisher's exact probability where cells contained less than five observations and therefore chi-square was unreliable, Field 2009)

It can be seen from Table 4-4 that the two groups Mild and Moderate created using the sentence intelligibility scores did not differ statistically significantly on

Table 4-4 Comparisons for gender, socioeconomic status and educational attainment (Mild and Moderate dysarthria) SIT

Variable	MILD		MODERATE		Test /Result	*P value (2-tailed)*
	Frequencies					
	Mn	sd	Mn	sd		
Age	69.2	9.0	68.9	9.0	**t = .10(41)**	**.92**
Gender						
Male	15		13		Pearson's χ^2 =.19 (1)	.66
Female	7		8			
Socio-economic classification						
A	0		0		Fisher's exact test	.40
B	0		1			
C1	5		7			
C2	**16**		**13**			
D	**1**		**0**			
E	**0**		**0**			
Education						
16	**7**		**11**		**Fisher's exact test**	**.33**
18	**9**		**5**			
Graduate	**6**		**4**			
Post-Graduate	**0**		**1**			

demographic variables and from Table 4-3 that they did not differ on variables related to development and progression of PD.

4.6.4 Mild and Moderate motor speech impairment (FDA)

Two groups of PD participants were identified using a median split of the scores for the Frenchay Dysarthria Assessment (FDA-2). This assessment is a measure of motor speech performance and hence is an index of speech impairment where intelligibility may be considered an index of disability.

The two groups were denoted 'Mild' for less severe motor speech impairment (n = 21) and 'Moderate' for more severe speech impairment (n = 22). Mild and Moderate groups were compared on possible confounding variables both related to presence of PD (cognition, apathy, anxiety, depression, functional physical ability, duration of PD and duration of signs of dysarthria) and unrelated to presence of PD (age, gender, socioeconomic status and education). Results for PD-related possible confounding variables and for age are reported in Table 4-6. As it cannot be predicted whether differences between these groups on such variables would be directional the p values are reported as 2-tailed. Non-parametric Mann Whitney tests were used where data sets being compared did not meet parametric requirements (see appendix 16)

Demographic variables

The mean age of the mildly-impaired group (n = 22) was slightly higher than that of the moderately impaired speakers (n = 21)

A t test indicated that the mildly and moderately impaired speakers with Parkinson's disease did not differ statistically significantly in terms of age $t(41) = -.14$, $p = .17$ (2 tailed)

While the distributions of participants in each category of other demographic variables differed slightly between groups chi-squared tests, or where appropriate Fisher's exact test, indicated that there was no significant relationship between severity of dysarthria measured using the FDA-2 and gender, socioeconomic category or educational attainment (see table 4-5)

Table 4-5 Comparisons for gender, socioeconomic status and educational attainment (Mild and Moderate dysarthria) FDA

Variable	MILD		MODERATE		Test /Result	*P value (2-tailed)*
	Mn	**sd**	**Mn**	**sd**		
Age	71.0	7.3	67.2	10.0	t = -.14(41)	**.17**
Gender						
	Frequencies					
Male	14		14		Yates' χ^2 =.04 (1)	.84
Female	7		8			
Total	21		22			
Socio-economic classification						
A	0		0		Fisher's exact test	.62
B	0		1			
C1	7		5			
C2	14		15			
D	0		1			
E	0		0			
Total	21		22			
Education						
16	9		9		Fisher's exact test	**.73**
18	6		8			
Graduate	6		4			
Post-Graduate	0		1			
Total	21		22			

Results in Table 4-6 show that, for the affective variables associated with PD and its progression, apathy, anxiety and depression moderately dysarthric speakers had slightly higher scores. However there was no statistically significant difference between the groups and effect sizes were small. Moderately dysarthric speakers had slightly lower scores for cognition but this difference was not statistically significant and had a small effect size indicating that the groups did not differ in cognitive level within the normal range. In order to evaluate further the effect of cognition and depression on the motor speech scores linear regression was carried out. This showed that correlation between FDA and cognition scores was weak (Pearson's $r = -.24$, $r^2 = .055$) and therefore cognition only accounted for approximately 5.5% of the variance of FDA scores. Linear regression showed that correlation between depression and FDA scores was also weak (Pearson's $r = -.09$, $r^2 = .007$) and therefore depression only accounted for approximately 0.7% of the variance of FDA scores.

Other variables which might be expected to index progression and severity of the general underlying pathology of PD were duration of PD since onset and the activities of daily living scale (PADLS) which is an indicator of overall mobility. Results showed a very small difference in means for activities of daily living and a longer duration since onset of PD in the moderately dysarthric group but neither of these reached statistical significance. Linear regression showed that

correlation between FDA and mobility scores was very weak (Pearson's r = -.05, r^2 = .003) which means that general mobility only accounts for approximately 0.3% of the variance of FDA scores suggesting that they are measuring distinct categories. Difference in duration since onset was approaching significance (p = .06) but the effect size was small (r =.24). Linear regression showed that correlation between FDA and time since onset was weak (Pearson's r = -.25, r^2 = .063) which means that time since onset only accounts for approximately 0.6% of the variance of FDA scores

Table 4-6 Comparisons for apathy, depression, mobility, duration PD, age at onset and duration speech signs using (Mild and Moderate dysarthria grouped using Frenchay Dysarthria Assessment [FDA])

	Mild		Moderate		*test*	*t val. df=41*	*z score*	*p (1 tail)*	*Effect size r*
	mean	*sd*	*mean*	*Sd*					
Cognition[1]	9.7	0.6	9.5	0.6	*U*		-1.30	.18	.20
Apathy[2]	-27.1	3.9	-26.4	3.4	*t*	-.61		.06	.09
Anxiety[3]	6.76	3.4	7.0	4.4	*t*	-.20		.42	.03
Depression[3]	4.0	2.0	4.5	1.7	*t*	-.80		.21	.12
Mobility[4]	2.5	.81	2.6	0.6	*U*		-.56	.58	.09
Duration PD[5]	93.7	51.4	123.1`	68.3	*t*	-1.6		.06	.24
Age at onset (yr)	63.5	9.5	57.5	11.9	*t*	1.81		.08	.27
Duration Speech[5]	55.4	49.2	68.1	68.6	*U*		-.48	.32	.72
Intelligibility[6]	95.5	4.3	88.3	16.9	*t*	1.93*		.03	.37

*equal variances not assumed
[1]SPMSQ Short Portable Mental Status Questionnaire
[2]LARS Lille Apathy Rating Scale
[3]HADS Hospital Anxiety and Depression Scale
[4]PADLS Parkinson's Disease Activities of Daily Living Scale
[5]Duration in months
[6] Transcribed sentence intelligibility

Age of onset may be significantly related to characteristics of PD. People with young onset of the disease have lower levels of depression, slower progression of disease and milder motor symptoms (Lewis et al., 2005) and so differences in age of onset may influence social participation through action of these variables. Mean age of onset for these groups did not place either group within Lewis et al's 'young onset' group (mean age at onset 50, sd 10 years) as can be seen in Table 4-6 above. There was no significant difference between these means, $t(41) = 1.8$, $p = .08$ (2 tailed) and so young onset characteristics are not likely to have influenced behaviour of either group.

Moderately dysarthric speakers did report longer mean duration of speech signs. The spread of the data for the duration of signs of speech impairment (and for the duration since onset of PD) was very large, as seen in the standard deviations in the table, indicating that the groups are relatively heterogeneous in relation to these variables. The more severely impaired group had experienced signs of speech impairment for longer than the less impaired group. Although this was not statistically significant ($p > .05$) there was a large effect size for this difference, $r = .72$ but the abnormal distribution of the data means that this should be interpreted with caution (Coe 2002). These groups also differed in sentence intelligibility, the more speech impaired group being significantly less intelligible than the mildly speech impaired group ($t(41) = 1.93$, $p = .03$, 1 tailed, $r = .37$). These two variables are also positively correlated (Pearson's $r = .39$, $p = .01$) and together these results indicate that motor speech impairment as

measured using the FDA is related to some extent to impact at the level of communicative activity.

Summary

The groups of mildly and moderately speech-impaired participants did not differ on demographic variables age, gender, socioeconomic status and education. They also did not differ on affective variables anxiety, depression and apathy or on disease-related variables of cognition, mobility, duration of PD and duration of speech changes. The results of the matching for these two groups suggest that while marking deterioration of speech production, the FDA scores were not indexing progression of other aspects of PD which are relevant to social functioning and therefore it is unlikely that any effects of motor speech impairment that are observed are the results of a 'third variable' such as overall severity of the disease. This does not mean that variables such as degree of motor impairment do not influence social behaviour in this sample but that any such effects should be broadly equal across the two speech impaired groups. Qualitative investigations may shed more light on the effects of motor involvement (see section 7).

4.7 Data Analysis

4.7.1 Processing of Data

Data were stored and processed using the SPSS (Ver. 18 and 19) statistics package.

4.7.2 Strategy for Selection of Statistical Tests.

First it was established that the groups for comparison (Control participants and all participants with PD, Mild and Moderate Dysarthric speakers) were matched on demographic variables which might have confounded the results (see section 4.6 above). The first research hypothesis was investigated by comparing the results of the non-neurologically impaired participants (Control group) with the results of all participants with dysarthria and PD (All PD group).The second research hypothesis was investigated in a similar way by comparing the results for the less and more severely dysarthric groups of speakers (Mild and Moderate).

Scores for social activity (SOCAT, appendix 13) and social network (convoy model, see appendix 14) were based on interval data: numerical counts of activities and network. Scores for social anxiety as measured using the IIS discomfort and frequency scales were based on a five point ordinal scale for each item (see appendix 15). Although interval level data is often cited as a requirement for parametric testing the parametric tests used in this study are robust with ordinal data of this kind (Norman, 2010). Decisions to use

parametric tests for these variables were therefore based on whether they satisfied the requirements of normality of distribution and equality of variances.

The data sets for the dependent variables were checked to see if they met parametric assumptions of normality and homogeneity of variance using appropriate statistical tests (see appendix 16 and 17). Parametric tests for independent samples were used wherever data met assumptions as these tests offer greater sensitivity than are normally more sensitive to differences between groups than non-parametric tests. Where homogeneity of variance was not certain, parametric equivalents which do not assume equality of variances were used (e.g. Welch's *F*) and this is indicated in the text. Where data were not normally distributed, a non-parametric alternative was used unless there are reasons to believe that the test is robust to violations of normality.

Where assumptions for parametric testing are met, ANOVA is a suitable technique for comparison of three or more groups, which is the case in the present study, and is more sensitive to true differences than multiple t tests (reduces type 1 error). However, in this study there are multiple dependent variables and therefore repeated ANOVAs for each dependent variable would increase the family-wise error rate and so increase the likelihood of a type 1 error, increasing the likelihood of detection of differences between groups which are not actually present. Multiple analysis of variance reduces the likelihood of type 1 error and in addition takes account of relationships between dependent variables which separate univariate ANOVAs cannot do as their analysis is

limited to a single variable. (In this study multiple analysis of variance was carried out using the General Linear Model, henceforth 'multivariate GLM) In this study the four main dependent variables all measure some aspect of social functioning and so it was anticipated that there would be relationships between social variables which can be explored. Multivariate GLM can indicate whether groups differ as a result of *combinations* of dependent variables, which adds to its power to detect a true difference between groups. Therefore, the first stage of analysis was to conduct a multivariate GLM. Where a significant difference between groups was detected by multivariate GLM this was followed up in two ways. First, univariate ANOVA was conducted on each variable with planned comparisons designed to test both hypothesis 1 by comparing Control with All PD speakers and to test hypothesis 2 by comparing Mild with Moderate dysarthric speakers. Second, discriminant function analysis (DFA) was carried out in order to see whether group differences were resulting from combinations of variables which represented previously unrecognised underlying dimensions (Green, Salkind, & Akey, 2008). DFA identifies those combinations of variables which discriminate the groups in the analysis and so can be used to generate substantive theoretical constructs and may be of particular relevance to this study where relationships between speech and social functioning are complex.

Any post hoc testing was conducted using the Games-Howell procedure which is best suited where group sizes are different (Field, 2009). In order to correct for family-wise error in post hoc testing a Bonferroni correction was applied to correct for inflation of type 1 error.

4.8 Summary

A group of 43 people with Parkinson's disease were recruited to investigate the effect of speech impairment on social variables. A control group of 30 neurologically normal participants were also recruited and these groups were matched for age, sex, socioeconomic status and education. All participants were screened for cognitive impairment, depression, and apathy and had no history of psychiatric or neurological illness, no co-occurring communication impairment or history, were not housebound and were first language speakers of English. The PD group were divided into higher and lower functioning groups (mild and moderate dysarthria) using (1) the Sentence Intelligibility Test and (2) the Frenchay Dysarthria Assessment. Groups were matched on the variables listed above. The independent variable for hypothesis 1 was presence or absence of PD with dysarthria. The independent variable for hypothesis 2 was severity of dysarthria. The main dependent variables for hypothesis 1 and 2 were number of social activities, number of members of social network, social anxiety (IIS-D social discomfort and IIS-F social avoidance). Further investigations carried out were: type and frequency of social activity; composition of social network (importance of members and relationship to participant); sub-categories of the scales for social anxiety (giving criticism, giving an opinion, giving a compliment, initiating a social contact, making a positive self-statement). Comparisons were made between the control group and all participants with PD to investigate hypothesis 1 and between mild and moderate dysarthric speakers to investigate hypothesis 2.

5 Chapter 5 Results of Quantitative Data

5.1 Introduction to Chapter

This chapter will present the results of analysis of quantitative data. Results for different groups were compared on the four main dependent variables: number of social activities, social network size, social anxiety (measured using the Inventory of Interpersonal Situations scales of discomfort and frequency). Comparison was made between the group of non-neurologically impaired participants and the group of all those with PD and dysarthria. This addressed the first research question, 'Does presence of dysarthria affect social variables? Secondly, comparison was made between a group of more severely dysarthric participants and a group of less severely dysarthric participants. This addressed the second research question, 'Does severity of dysarthria affect social variables?'

First, the approach to investigation of the research questions and the rationale for methods of testing differences between means are described. The research hypotheses were initially tested in relation to the four main dependent variables using multivariate and univariate analysis with planned comparisons, post hoc comparisons where appropriate and discriminant function analysis. Descriptive statistics are presented for all groups and then the sequence of statistical tests for each variable is reported. Following testing of the main dependent variables, further investigation of sub-categories within the main results is reported as appropriate. Results are presented which address the research questions first

using intelligibility (SIT) as the measure of dysarthria severity. Then results are presented where the measure of severity is based on oromotor functioning (FDA). Finally, significant findings are summarised at the end of the chapter. Interpretation of the results and integration with the qualitative findings will be found in section 8.

5.2 Hypothesis testing using intelligibility as measure of dysarthria severity

First, data were investigated using intelligibility scores from the SIT to divide the participants with PD into moderately and mildly dysarthric groups, Moderate (Intel) and Mild (Intel) respectively.

5.2.1 Descriptive Statistics

Table 5-1 shows the means and standard deviations for the four main dependent variables. Differences in the means are in the predicted direction in each case. Participants with PD and dysarthria reported fewer social activities, smaller social networks, greater social discomfort and greater social avoidance than neurologically unimpaired participants dysarthric speakers as a whole (Hypothesis 1). The same pattern of differences was observed comparing the Mild dysarthric and Moderate dysarthric speakers (Hypothesis 2). The mean size of social network in the Mild (Intel) group is unexpectedly higher than that of the control group.

It should be noted that the dispersion of the social network data is relatively high as indicated by the standard deviations in each group. Range of data is

Table 5-1 Means and standard deviations for main dependent variables, all groups

	Hypothesis 1				Hypothesis 2			
Variable	**Control**		**All PD**		**Mild (Intel)**		**Moderate (Intel)**	
	Mn	**sd**	**Mn**	**sd**	**Mn**	**sd**	**Mn**	**sd**
SOCACT total	**18.4**	**4.2**	**17.1**	**4.3**	**17.6**	**4.5**	**16.5**	**4.1**
Network total	**28.1**	**13.6**	**27.3**	**13.0**	**29.4**	**14.0**	**25.1**	**11.2**
IIS Discomfort	**63.4**	**15.2**	**72.9**	**23.4**	**73.0**	**23.2**	**72.9**	**24.3**
IIS Frequency*	**106.0**	**14.9**	**99.1**	**17.9**	**103.9**	**17.2**	**94.1**	**17.7**

*lower scores indicate higher levels of social avoidance

presented in table 5-2. It can be seen that the range of scores for both control and dysarthric participants is large for all variables. In addition, participants with PD and dysarthria have a lower minimum for social activity, social network and IIS-Frequency and a higher maximum for IIS-Discomfort all of which indicate that this group includes the participants with the least activity, smallest network, greatest avoidance of social situations and highest discomfort in social situations.

Table 5-2 Range of scores for main dependent variables, all groups

Variable	**Control**		**All PD**		**Mild (Intel)**		**Moderate (Intel)**	
	Min	**Max**	**Min**	**Max**	**Min**	**Max**	**Min**	**Max**
SOCACT total	11	30	3	28	10	28	3	23
Network total	13	63	8	66	11	66	8	54
IIS Discomfort	38	98	36	131	40	131	36	114
IIS Frequency*	82	137	54	141	83	141	54	123

*lower scores indicate higher levels of social avoidance

Differences between groups were tested accordingly.

5.2.2 Multivariate Analysis

Multiple analysis of variance using the General Linear Model (GLM), (henceforth 'multivariate GLM') was conducted comparing the results for the three groups Control, Mild (Intel) and Moderate (Intel). This method of anlaysis was chosen because multivariate GLM is sensitive to relationships between variables as well as differences between groups. Variables tested using multivariate GLM should be conceptually related but not more than moderately correlated to avoid the problems of multiple collinearity. All four of the dependent variables are related to each other as different aspects of social functioning, however they were not strongly correlated with each other in this study as can be seen from table 5-3 where all correlations are below .5.

Table 5-3 Correlations between dependent variables (Pearson's *r*)

	Social Network	IIS D	IIS F
SOCACT total	.235	-.062	.418
Network total		-.162	.382
IIS Discomfort			-.266

Box's test for homogeneity of covariance matrices was non-significant (*M*=27.3, *F*= 1.2 (20,14670), *p*=.20) indicating homogeneity of variance between groups and therefore, for unequal group sizes as in this study, Pillai's trace is the most accurate multivariate statistic to use (Bray & Maxwell, 1985). Tests of normality showed that data sets have normal distribution except for Control group network total. There is thus a small degree of violation of multivariate normality but the multivariate GLM test statistics are held to be relatively robust to violations of

multivariate normality (Field, 2009) and therefore it was decided to carry out the procedure.

Against prediction, using Pillai's trace, there was no significant effect of intelligibility on number of social activities, size of social network, social anxiety and social avoidance, $V = 0.14$, $F(8,136) = 3.12$, $p = .26$

Follow-Up Analysis

As multivariate analysis did not reveal relationship between the main variables each was investigated separately using univariate ANOVA with planned contrasts to test each experimental hypothesis. Although some data sets as detailed above were not normally distributed (see table 5-1 above) ANOVA is relatively robust to violations of assumptions and so the procedure was carried out with the following results.

There was no overall effect of dysarthria on number of social activities, $F(2,70) = 1.3$, $p = .29$.

There was no overall effect of dysarthria on social network size, $F(2,70) = .6$, $p = .55$.

There was no overall effect of dysarthria on social discomfort, $F(2,70) = 1.9$, $p = .16$.

There was an overall effect of dysarthria on social avoidance, $F(2,70) = 3.5$, $p = .04$.

5.2.3 Planned Contrasts: testing Hypothesis 1 and 2

Planned contrasts were carried out to investigate hypothesis 1 (that presence of dysarthria will affect social variables) and hypothesis 2 (that severity of dysarthria will affect social variables).

Hypothesis 1

Comparing the control group with all participants with PD, the results of the planned contrasts showed that there was a significant effect of *presence* of dysarthria for social discomfort (IIS-D) $t(70) = 2.1$, $p = .02$, and also for social avoidance (IIS-F) $t(70) = 1.8$, $p = .04$ but not for social activity or network (*p>.05)* see table 5-4.

Table 5-4 Differences in main dependent variable, control and all PD participants

	Control		All PD				*p 1 tail*	***effect r***
	Mean	StDev	Mean	StDev	*t*	*df*		
SOCACT total	18.4	4.2	17.1	4.3	1.35	71	.09	0.16
Network total	28.1	13.6	27.3	13.0	.24	71	.40	0.03
IIS Discomfort	63.4	15.2	72.9	23.4	-2.1*	71	.02	0.24
IIS Frequency**	106.0	14.9	99.1	17.9	1.74	71	.04	0.20

*Equal variances not assumed
** lower scores indicate higher social avoidance

Hypothesis 2

Comparing the mild with moderate dysarthric groups the results of the planned contrasts showed that there was a significant effect of *severity* of dysarthria on social avoidance (IIS-F), $t(70) = 2.0$, $p = .03$ (1 tailed). There was no significant effect of severity of dysarthria for social activity, social network or discomfort (IIS-D) $p>.05$ (see table 5-5).

Table 5-5 Comparisons for main dependent variables, Mild (Intel) and Moderate (Intel) dysarthria.

	Mild (Intel)		Moderate (Intel)				*p 1 tail*	***effect r***
	Mean	StDev	Mean	StDev	*t*	*df*		
SOCACT total	17.8	4.9	16.5	4.1	-1.01	70	.16	0.12
Network total	29.4	14.0	25.1	11.8	-1.07	70	.40	0.13
IIS Discomfort	73.0	23.2	72.9	24.3	-.01*	40.6	.50	0.00
IIS Frequency**	103.9	17.2	94.1	17.7	-1.95	70	.03	0.23

*equal variances not assumed
** lower scores indicate higher social avoidance

5.2.4 Further Investigations

As there was no evidence of group differences shown by univariate ANOVA for social activity and social network the sub-categories of these variables were not explored further to investigate the research hypotheses. Further data testing the impact of presence of dysarthria on social activity and social network subcategories will be presented in section 5.3.7 and following, below. However, the variable 'cumulative frequency' of social activity is not a simple sub-category of the total number of social activities and was therefore investigated separately, see table 5-6.

Table 5-6 Cumulative Frequency of Social Activity by Group

	Hypothesis 1				Hypothesis 2			
Variable	**Control**		**All PD**		**Mild (Intel)**		**Moderate (Intel)**	
	Mn	**sd**	**Mn**	**sd**	**Mn**	**sd**	**Mn**	**sd**
Social Activity cumulative frequency	54.8	15.0	51.5	15.6	55.9	15.5	47.0	14.7

Means for cumulative frequency of social activity differed in the predicted directions, however univariate ANOVA showed no significant effect of group on this variable, $F(2,70) = 2.26$, $p = .11$. Planned contrasts revealed that there was a significant effect of severity of dysarthria, $t(70) = 1.93$, $p = .03$ (1 tailed) but not of presence of dysarthria , $t(70) = .93$, $p = .18$ (1 tailed).

As there was some evidence of differences between groups for social anxiety in relation to hypothesis 1, further comparisons were made of sub-categories of the IIS discomfort and frequency scales. Means and standard deviations of all sub-categories for all groups are shown in table 5-7. Observed differences do not consistently follow predicted directions.

Table 5-7 Means and standard deviations for IIS sub-scales

	Hypothesis 1				Hypothesis 2			
	Control		All PD		Mild (Intel)		Moderate (Intel)	
	Mean	StDev	Mean	StDev	Mean	StDev	Mean	StDev
IIS-Discomfort								
Criticising	2.5	0.8	2.6	0.8	2.6	0.9	2.6	0.9
Giving opinion	1.9	0.6	2.2	0.9	2.3	0.9	2.0	0.9
Complimenting	1.3	0.4	1.5	0.4	1.4	0.3	1.4	0.4
Initiating	1.4	0.3	1.9	0.8	2.0	0.8	1.9	0.7
Positive self-statement	1.8	0.5	2.0	0.7	1.9	0.7	2.0	0.7
IIS-Frequency*								
Criticising	2.2	0.5	2.4	0.5	2.2	0.5	2.3	0.5
Giving opinion	2.7	0.6	2.6	0.5	3.7	0.5	2.8	0.6
Complimenting	3.6	0.6	3.7	0.7	3.5	0.7	3.6	0.7
Initiating	3.3	0.5	3.1	0.8	2.8	0.7	3.0	0.7
Positive self-statement	3.2	0.5	3.1	0.6	2.8	0.6	2.9	0.6

* lower scores indicate higher social avoidance

Univariate ANOVA with planned contrasts to test the two experimental hypotheses was carried out for these sub-scales. This analysis revealed that there was a significant effect of dysarthria between groups only for the sub-category 'Initiating Contact' (see table 5-8)

Planned contrasts showed that presence of dysarthria (Control, All PD) increased discomfort when initiating social contacts and decreased reported frequency of initiating social contact (see table 5-9). Presence of dysarthria also decreased reported frequency of making positive self-statements to others.

Table 5-8 IIS Sub-scales, results of univariate ANOVA

			2 tail
	F	*df*	*p*
IIS-Discomfort			
Criticising	.12	2,70	.89
Giving opinion	1.46	2,70	.24
Complimenting	.1.10	2,70	.34
Initiating	6.08	2,70	<.01
Pos. self-statement	.92	2,70	.40
IIS-Frequency		2,70	
Criticising	.84	2,70	.44
Giving opinion	1.47	2,70	.24
Complimenting	1.58	2,70	.21
Initiating	3.46	2,70	.04
Pos. self-statement	2.54	2,70	.09

Table 5-9 IIS Sub-scales, comparisons for hypothesis 1, presence of dysarthria

	Control		**All PD**				***1 tail***	
	Mean	StDev	Mean	StDev	*t*	*df*	*p*	*r*
IIS-Discomfort								
Criticising	**2.5**	**0.8**	**2.6**	**0.9**	-.39	70	.35	0.05
Giving opinion	**1.9**	**0.6**	**2.0**	**0.9**	-1.80*	70	.04	0.21
Complimenting	**1.3**	**0.4**	**1.4**	**0.4**	-1.12	70	.14	0.13
Initiating	**1.4**	**0.3**	**1.9**	**0.7**	-3.93*	70	<.001	0.43
Pos. self-statement	**1.8**	**0.5**	**2.0**	**0.7**	-1.18	70	.12	0.14
IIS-Frequency								
Criticising	**2.2**	**0.5**	**2.3**	**0.5**	-.23	70	.41	0.03
Giving opinion	**2.7**	**0.6**	**2.8**	**0.6**	-.41	70	.35	0.05
Complimenting	**3.6**	**0.6**	**3.6**	**0.7**	1.45	70	.07	0.17
Initiating	**3.3**	**0.5**	**3.0**	**0.7**	2.36	70	.01	0.27
Pos. self-statement	**3.2**	**0.5**	**2.9**	**0.6**	1.95	70	.03	0.23

*Equal variances not assumed
** lower scores indicate

There were no significant differences in IIS sub-scales between the Mild (Intel) and Moderate (Intel) groups (see table 5-10) and so it can be concluded that severity of dysarthria measured by sentence intelligibility had no impact on social anxiety in this sample.

Table 5-10 IIS Sub-scales, comparisons for hypothesis 2, severity of dysarthria

	Mild (Intel)		**Moderate (Intel)**				***1 tail***	
	Mean	StDev	Mean	StDev	*t*	*df*	*p*	*r*
IIS-Discomfort								
Criticising	**2.6**	**0.8**	**2.6**	**0.9**	-.31	70	.38	0.04
Giving opinion	**2.2**	**0.9**	**2.3**	**0.9**	.30	70	.36	0.04
Complimenting	**1.5**	**0.4**	**1.4**	**0.3**	-.98	70	.33	0.12
Initiating	**1.9**	**0.8**	**2.0**	**0.8**	-.52	70	.30	0.06
Pos. self-statement	**2.0**	**0.7**	**1.9**	**0.7**	-.67	70	.25	0.08
IIS-Frequency*								
Criticising	**2.4**	**0.5**	**2.2**	**0.5**	-1.28	70	.10	0.15
Giving opinion	**2.6**	**0.5**	**3.7**	**0.5**	-1.66	70	.50	0.19
Complimenting	**3.7**	**0.7**	**3.5**	**0.7**	-1.03	70	.15	0.12
Initiating	**3.1**	**0.8**	**2.8**	**0.7**	-1.16	70	.13	0.14
Pos. self-statement	**3.1**	**0.6**	**2.8**	**0.6**	-1.13	70	.13	0.13

*Equal variances not assumed
** lower scores indicate

5.2.5 Summary

Using intelligibility as a measure of dysarthria severity it was found that although group means for the main dependent variables of social activity, social network size, discomfort in social situations and avoidance of social situations differed in the predicted directions there were few statistically significant differences. Results of multivariate analysis of variance (GLM) showed no significant relationship between dependent variables on these groups i.e. no combined effect of the variables. Univariate analysis of variance with planned contrasts for

each variable showed that presence of dysarthria (hypothesis 1) negatively affected social discomfort (IIS-D) and social avoidance (IIS-F) and severity of dysarthria (hypothesis 2) negatively affected social avoidance alone. Further investigation showed that severity of dysarthria negatively impacted frequency of social activity. Investigation of the social anxiety (IIS) sub-scales showed that presence of dysarthria, but not severity significantly negatively affected only the sub-scale 'initiation of social contact' both in terms of increased discomfort and higher avoidance. Presence of dysarthria, but not severity, negatively affected avoidance of situations involving making positive self-statements.

5.3 Hypothesis testing using severity of motor speech impairment

Next, data were investigated using scores from the FDA to divide the participants with PD into moderately and mildly dysarthric groups, Moderate (FDA) and Mild (FDA) respectively. The rationale for carrying out this analysis was threefold: (1) intelligibility is a measure of activity or of impact but not of underlying speech impairment; (2) previous studies have not found that intelligibility is related to psychosocial functioning; (3) distribution of intelligibility data in the current sample may mask underlying speech impairment. It is recognised that using either intelligibility or FDA scores to measure speech impairment is theoretically problematic (Ziegler, 2003; Ballard et al., 2003; Weismer, 2006) nevertheless motor speech functioning is an accepted measure of relevant impairment in dysarthria (Hartelius & Miller, 2011). This is discussed in more detail in section 8 below.

As detailed above, the strategy for analysis consisted of first carrying out a multivariate GLM which has greater power to detect true differences between groups than univariate tests. In order to focus analysis on the two experimental hypotheses multivariate GLM was followed up by univariate analysis of variance (ANOVA) with planned contrasts to investigate experimental hypotheses. In addition, underlying dimensions which represented relationships between variables which discriminated the groups were investigated using discriminant function analysis.

5.3.1 Descriptive Statistics

Table 5-11 shows the means and standard deviations for the four main dependent variables. Considering hypothesis 1 and therefore comparing Control with All PD participants we can see differences in the means which are in the predicted direction in each case i.e. participants with PD and dysarthria reported fewer social activities, smaller social networks, greater social anxiety and greater social avoidance than dysarthric speakers as a whole. Considering the Mild (FDA) and Moderate (FDA) speakers, means are also in the predicted direction i.e. moderately dysarthric speakers reported fewer social activities, smaller social networks, greater social anxiety and greater social avoidance than mildly dysarthric speakers.

It should be noted that the dispersion of the social network data is relatively high as indicated by the standard deviations in each group. The mean size of social network in the Mild group is unexpectedly higher than that of the control group.

Table 5-11 Means and standard deviations for main dependent variables, all groups based on FDA split

	Hypothesis 1				Hypothesis 2			
Variable	**Control**		**All PD**		**Mild (FDA)**		**Moderate (FDA)**	
	Mn	**sd**	**Mn**	**sd**	**Mn**	**sd**	**Mn**	**sd**
SOCACT total	18.4	4.2	17.1	4.3	18.3	3.8	15.9	4.4
Network total	28.1	13.6	27.3	13.0	37.3	13.3	22.5	8.1
IIS Discomfort	63.4	15.2	72.9	23.4	70.5	23.0	75.2	24.1
IIS Frequency*	106.0	14.9	99.1	17.9	99.7	16.4	98.6	19.6

*lower scores indicate higher levels of social avoidance

Differences between means were tested accordingly.

5.3.2 Multivariate and univariate analysis of variance

A multivariate GLM was conducted comparing the results for the three groups Control, Mild (FDA) and Moderate (FDA). Variables tested using multivariate GLM should be conceptually related but not more than moderately correlated to avoid the problem of multiple collinearity where high correlation between the predictor variables reduces the power of the analysis. All four of the dependent variables were related to each other as different aspects of social functioning, however they are not strongly correlated with each other as can be seen from table 5-12 where all correlations are below .5.

Table 5-12 Correlations between dependent variables (Pearson's *r*)

	Network Total	**IIS Discomfort**	**IIS Frequency**
SOCACT Total	.235	-.062	.418
Network Total		-.162	.382
IIS Discomfort			-.266

Homogeneity of variance between groups is required for multivariate GLM. Box's test for homogeneity of covariance matrices was non-significant (M=26.5,

F= 1.2 (20,14670), p=.23) indicating homogeneity of variance and therefore, for unequal group sizes which is the case in this study, Pillai's trace is the most accurate multivariate statistic to use (Bray and Maxwell, 1985). Tests of normality showed that data sets have normal distribution except for Control group network total, Moderate dysarthria group social activity and Mild dysarthria group interpersonal discomfort. There is thus a small degree of violation of multivariate normality but the multivariate GLM test statistics are held to be relatively robust to violations of multivariate normality (Field, 2009) and therefore it was decided to carry out the procedure.

Using Pillai's trace, there was a significant effect of dysarthria severity measured by motor speech performance on number of social activities, size of social network, social anxiety and social avoidance (see table 5-11 above for means and standard deviations), $V = 0.31$, $F(8,136) = 3.12$, $p = .003$.

Follow-Up Analysis

Two possible methods of follow-up analysis were considered: to examine group differences in each variable using univariate ANOVA and to examine combinations of variables using discriminant analysis. First, univariate ANOVAs with planned contrasts and post hoc comparisons between groups were carried out to investigate whether group differences arose from individual social variables.

Results of ANOVAs

Univariate ANOVA was carried out on the four main dependent variables. Although some data sets as detailed above were not normally distributed (see table 5-11 above) ANOVA is relatively robust to violations of assumptions (Norman, 2010) and so the procedure was carried out with the following results.

There was an overall effect of dysarthria severity on social network size, $F(2,70) = 6.2$, $p = .003$.

There was no overall effect of dysarthria severity on number of social activities, $F(2,70) = 2.7$, $p = .08$.

There was no overall effect of dysarthria severity on social anxiety, $F(2,70) = 2.2$, $p = .12$.

There was no overall effect of dysarthria severity on social avoidance, $F(2,70) = 2.7$, $p = .23$.

Planned Contrasts

Planned contrasts were carried out to investigate hypothesis 1 (that presence of dysarthria will negatively affect social variables) and hypothesis 2 (that severity of dysarthria will negatively affect social variables).

5.3.3 Hypothesis 1

Comparing the control group with all participants with PD, the results of the planned contrasts have already been reported in section 5.2.3 above but are repeated here for convenience.

Table 5-13 Dependent variables, comparisons for Control and PD groups

	Control		All PD				1 tail	
	Mean	StDev	Mean	StDev	*t*	*df*	*p*	*r*
SOCACT total	18.4	4.2	17.1	4.3	1.35	71	.09	0.16
Network total	28.1	13.6	27.3	13.0	.24	71	.40	0.03
IIS Discomfort	63.4	15.2	72.9	23.4	-2.1*	71	.02	0.24
IIS Frequency**	106.0	14.9	99.1	17.9	1.74	71	.04	0.20

*Equal variances not assumed
** lower scores indicate higher social avoidance

It can be seen from table 5-13 that for number of social activities (SOCACT total) and for size of social network (Network Total) there was no significant difference between the control group and the participants with PD and dysarthria as in both cases $p > .05$. Presence of PD and dysarthria did result in significantly greater social anxiety (IIS Discomfort) and increased social avoidance (IIS Frequency) $p < .05$ in each case.

5.3.4 Hypothesis 2

Table 5-14 below contains the planned contrasts for each dependent variable for the Mild (FDA) and Moderate (FDA) dysarthric groups

Table 5-14 Dependent variables, comparisons for Mild and Moderate (FDA) groups

	Mild (FDA)		Moderate (FDA)		t	df	*p* (1-tailed)	*effect r*
	Mean	sd	Mean	sd				
SOCACT Total	18.3	3.8	15.9	4.4	-1.9	70	.057	0.22
Network Total	37.3	13.3	22.5	8.1	-3.4	70	<.01	0.38
IIS Discomfort	70.5	23.0	75.2	24.1	.80	70	.49	0.10
IIS Frequency	99.7	16.4	98.6	19.6	-.14	70	.89	0.02

It can be seen severity of dysarthria did result in significantly smaller social network size, $t(70) = -3.4$, $p < .05$ but that for number of social activities (SOCACT total), for social anxiety (IIS Discomfort) and for social avoidance (IIS Frequency) there was no significant effect of dysarthria severity (FDA), in all cases $p > .05$.

Summary

In summary, the results from univariate ANOVA showed that there was an overall effect of presence of PD and dysarthria on social network size but no overall effect on number of social activities, social anxiety or social avoidance. The results of the planned contrasts for the Control group and all participants with PD showed that there was an effect of presence of PD with dysarthria on social anxiety (discomfort and avoidance) but not on social network size or on number of social activities. The results of the planned contrasts for Mild (FDA) and Moderate (FDA) groups showed that there was an effect of severity of dysarthria on social network size but no effect was seen on total number of

social activities or overall social anxiety (either discomfort or frequency). Therefore, the results from univariate ANOVA and planned contrasts suggest that the group effect seen in the multivariate GLM is not simply due to differences in separate dependent variables but that the relationship between these variables is likely to be important too. It is reasonable to suppose that the dependent variables, which are all measures of social functioning, may represent some underlying dimension or dimensions which give rise to the significant multivariate GLM. Therefore, in addition to univariate ANOVAs, follow-up analysis was also conducted using discriminant function analysis which treats the dependent variables in combination rather than separately.

5.3.5 Discriminant Function Analysis

Discriminant analysis is a method used to make a probabilistic prediction about category membership from a combination of continuous predictor variables (Green et al 2008). In this study it was used to investigate whether membership of the different groups Control, Mild and Moderate could be predicted on the basis of the data collected for number of social activities, social network size, social anxiety and social avoidance.

Assumptions for discriminant analysis are the same as for multivariate GLM and so the assumptions of multivariate normality, homogeneity of covariances, multi-collinearity and independence of variables were satisfied as detailed above.

Results of Discriminant Function Analysis (DFA)

DFA revealed two discriminant functions. The first function explained 74% of the variance, canonical R^2 = .21, and the second function explained 26% of the variance, canonical R^2 = .08. Taken in combination, these discriminant functions significantly differentiated the speaking groups, $\Lambda = .72, \chi^2(8) = 22.2, p < .01$. With the second function removed the speaking groups were not significantly differentiated, $\Lambda = .92, \chi^2(3) = 6.1, p = .11$. Therefore the group differences shown in the multivariate GLM can be explained in terms of two underlying dimensions working in combination.

The correlations between outcomes and discriminant functions from the structure matrix (the canonical variate correlation coefficients, see table 5-15) revealed that social network loaded strongly onto the first function whereas social anxiety (IIS discomfort) and social avoidance (IIS frequency) loaded strongly onto the second function. Social activity (SOCACT total) loaded moderately and equally onto both functions but in different ways, as indicated by the positive and negative signs. The first function differentiates social network and activity from social anxiety and avoidance, whereas the second function differentiates social activity, anxiety and avoidance from social network.

Table 5-15 Discriminant functions structure matrix: canonical variate correlation coefficients

	Function	
	1	**2**
Social Network total	.82	.04
SOCACT total	.47	-.46
IIS Discomfort	-.22	.73
IIS Frequency	.09	-.66

A combined-groups plot was generated (figure 5-1) which displays the variate scores for each person (circles) coded by group (colours), and the mean variate scores for groups, the group centroids (squares). The combined groups plot showed that the first function discriminated the moderately-impaired speakers from the mildly-impaired speakers (horizontal distance) and the second function discriminated the control group from the two speech-impaired groups (vertical distance).

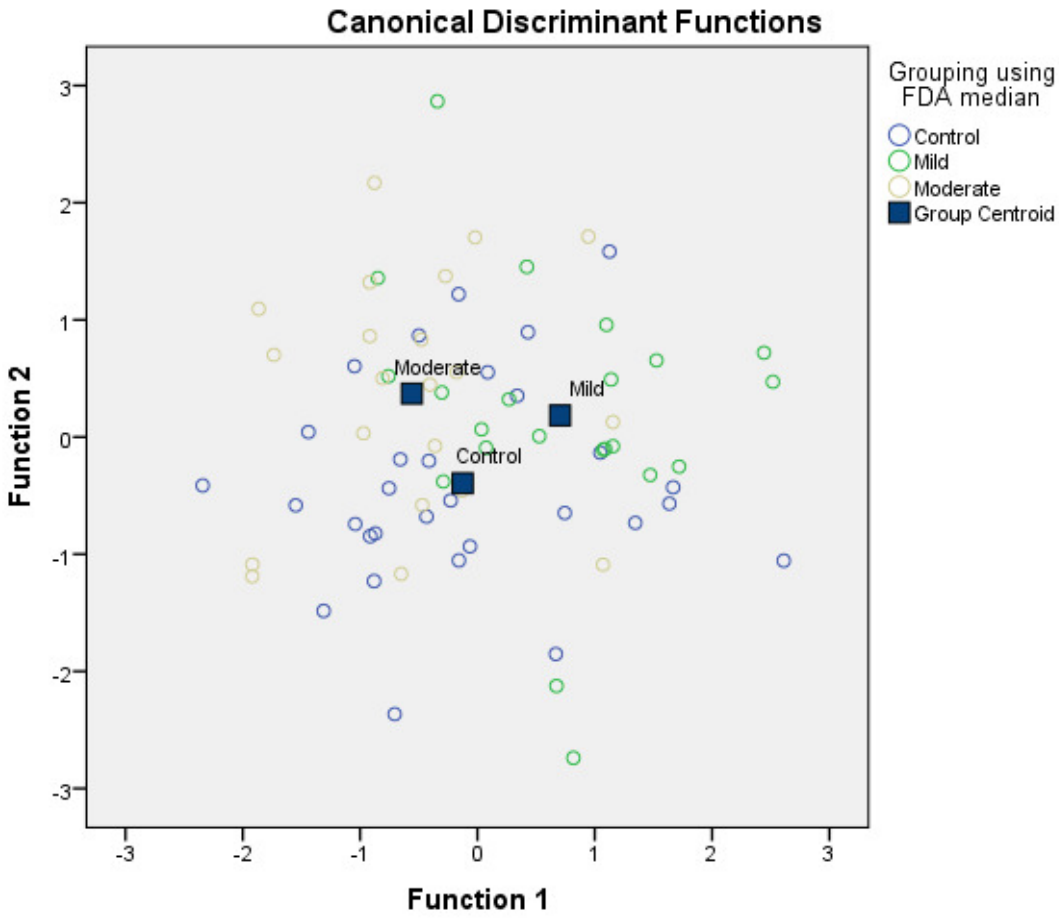


Figure 5-1 Canonical Discriminant Functions

The first function, therefore, appears to be related to social capital in that quantitative dimensions of social functioning - the number of people in one's social network and, to a lesser extent, the range of social activities engaged in - contribute strongly to this variate. This function most strongly differentiates participants on the basis of the severity of their motor speech impairment. The second function appears to be related to social anxiety in that discomfort in and avoidance of social situations contribute strongly to this variate. This function most strongly differentiates those with and without PD-associated motor speech impairment. These discriminant functions will be discussed in more detail in relation to the results of the qualitative data analysis later in the thesis.

5.3.6 Further Investigation of Dependent Variables

The positive results of the multivariate GLM and discriminant function analyses suggested that further exploration of the sub-categories of the main dependent variables should be undertaken in order to specify whether certain aspects of these variables were of greater importance. The data that was collected for social activity and social network included not only the total number of activities and members of the network but also subcategories of type of activity and composition of social networks. Within the SOCACT, social activities were categorised as either belonging to a 'leisure', 'informal group' or 'formal group' following Cruice et al (2006). Additionally, data were collected allowing a cumulative monthly frequency of all activities to be calculated. Within the social network, participants allocated members to three categories: an inner circle, a middle circle and an outer circle according to how close and important they

were to the participant using the definitions provided by Antonucci and Akiyama (1987). In addition, information was collected on whether network members were close family (spouse/partner, child, parent, sibling), other relative, friend or 'other' (all other social contacts). The Inventory of Interpersonal Situations discomfort and frequency scales are composed of five sub-categories of social situations:

- Criticising others
- Giving an opinion
- Giving a compliment
- Initiating a social contact
- Making a positive self-statement

Knowing whether dysarthria impacted these sub-categories in different ways was important as the overall totals for the four main variables provide a very simplistic account of social functioning and evidence suggests that other communication disorders do affect activity type and network composition (Cruice et al, 2006)

5.3.7 Type of Social activity

Mean number of activities in each of the categories 'leisure, informal and formal' were calculated and the results are presented in table 5-16 It can be seen from table 5-16 that the leisure category is consistently the largest as a proportion of the total number of activities recorded and that the formal category is the smallest in all groups. Differences in means between groups can be seen for

Table 5-16 Means and standard deviations for social activity sub-categories, all groups (FDA)

	Hypothesis 1				Hypothesis 2			
Variable	**Control**		**All PD**		**Mild (FDA)**		**Moderate (FDA)**	
	Mn	**sd**	**Mn**	**sd**	**Mn**	**sd**	**Mn**	**sd**
SOCACT total	18.4	4.2	17.1	4.3	18.3	3.8	15.9	4.4
Leisure	12.3	2.2	10.8	2.8	11.5	2.8	10.1	2.6
Informal	3.9	1.9	4.3	1.5	4.3	1.3	4.3	1.6
Formal	2.2	1.6	1.9	1.5	2.4	1.4	1.4	1.5

the leisure category which are in the predicted direction i.e. Hypothesis 1: Control > All PD and Hypothesis 2: Mild (FDA)> Moderate (FDA). This pattern is also repeated for the 'Formal' group category. However, the participants with PD reported a larger number of informal group activities than the control group and this was the case irrespective of severity of dysarthria. It is worth noting that the informal category of social activity included attendance at meetings of charitable organisations such as Parkinson's UK , which applied to many of this sample. In order to investigate these differences and establish whether any statistically significant differences existed the data were investigated using multivariate GLM, univariate GLM and post hoc testing.

A multivariate GLM was conducted comparing the results for the three sub-categories of social activity, leisure, informal groups and formal groups. Variables tested using multivariate GLM should be conceptually related but not more than moderately correlated to avoid the problem of multiple collinearity. All three of the dependent variables were related to each other as different aspects of social activity, however they are not strongly correlated with each other as can be seen from table 5-17 where all correlations are below .5.

Table 5-17 Correlations between sub-categories of social activity

	Informal	Formal
Leisure	.16	.43
Informal		.33

Box's test for homogeneity of covariance matrices was non-significant (M=18.04, F= 1.4 (12,19412.7), p=.154) indicating homogeneity of variance between groups and therefore, for unequal group sizes which is the case in this study, Pillai's trace was used. Tests of normality and of equality of variance showed that data sets have normal distribution and equal variances (see appendix 16 and 17) and therefore it was decided to carry out the procedure.

Using Pillai's trace, there was a significant effect of dysarthria severity measured by motor speech performance on number of social activities in the sub-categories leisure, informal and formal, $V = 0.25$, $F\,(6,138) = 3.21$, $p = .006$.

In order to understand where the differences lay, univariate tests were conducted for each sub-category and the results were as follows:

There was an overall effect of group on number of leisure activities, $F(2,70) = 4.6$, $p = .01$.

There was no overall effect of group on number of informal group social activities, $F(2,70) = .56$, $p = .58$

There was an overall effect of group on number of formal group social activities, $F(2,70) = 4.4$, $p = .02$

As univariate tests were significant for the sub-categories of leisure activities and formal group social activities planned contrasts are reported for these variables (see table 5-18). These showed that there were effects of both presence of dysarthria and severity of dysarthria. Participants with PD reported significantly fewer activities than control participants in the leisure category. Moderately dysarthric participants reported significantly fewer activities than mildly dysarthric participants in the leisure and formal social group categories. There were no differences between groups in the informal social group category despite the high number of participants with PD who attended meetings of PD support groups.

Table 5-18 Planned contrasts, sub-categories of social activity (FDA grouping)

	Contrast	t	df	Sig. (1-tailed)	Effect *r*
SOCACT Leisure	Control - All PD	2.398	70	.01	0.28
	Mild - Moderate	-1.806	70	.04	0.21
SOCACT Informal	Control - All PD	-.978	70	.17	0.12
	Mild - Moderate	-.029	70	.48	0.00
SOCACT Formal	Control - All PD	.856	70	.39	0.10
	Mild - Moderate	-2.127	70	.02	0.25

Summary

Investigation of sub-categories of social activity using multivariate analysis, unvariate analysis and planned contrasts revealed that there was an effect of presence of dysarthria on number of leisure activities and an effect of dysarthria severity on number of leisure activities and formal group activities. There was no effect of presence or severity of dysarthria on informal social group activities.

5.3.8 Frequency of social activity

A cumulative monthly figure for frequency of activity was calculated for each participant as detailed in section 4.3.1 above. Means for each group are shown in table 5-19.

Table 5-19 Means and standard deviations, social activity frequency, all groups (FDA)

	Hypothesis 1				Hypothesis 2			
	Control		All PD		Mild (FDA)		Moderate (FDA)	
	Mn	Sd	Mn	sd	Mn	sd	Mn	sd
Monthly cumulative frequency	54.8	15.1	54.7	15.0	60.1	15.7	43.4	10.5

From table 5-19 it can be seen that there was relatively little difference between the control group mean and that of the All PD group or the Mild dysarthric group. However, the cumulative total for the moderate dysarthric group was considerably lower. Kolmogrov-Smirnov tests showed that data sets were normally distributed and Levene's test showed that variances were homogenous. Therefore, differences in means were investigated first using univariate analysis of variance which revealed a significant effect of group on monthly cumulative activity level. $F(2) = 8.20$, $p = .001$. This was followed up by planned contrasts investigating the two research hypotheses. These showed that there was no effect of presence of dysarthria (Control group, All PD), $t\,(70) = .64$, $p = .26$ (1 tailed), $r = .08$. However, there was a significant effect of severity of dysarthria on cumulative monthly frequency of social activity, $t\,(70) = -3.99$, $p = <.001$ (1 tailed), $r = .43$

Post hoc tests were carried out using the Games-Howell procedure because group sizes were different. This confirmed that there was no significant difference between the control group and the Mild dysarthric group, $p = .46$ but there was a significant difference between the Control group and the Moderate (FDA) dysarthric group, $p = .01$ after Bonferroni correction.

In summary, the results for cumulative activity frequency showed that severity of dysarthria (FDA) negatively impacted frequency of social activity but presence of dysarthria (FDA) did not. Moderately dysarthric participants were significantly less active than both other groups of participants.

5.3.9 Composition of social network: closeness and importance of members

Data were collected on numbers of people in participants' social networks whom the participants classified as being within three categories of closeness and importance in their life. These were referred to as 'Inner', 'Middle' and 'Outer' circles as detailed in section 4.3.2. Mean number of people in each of the circles was calculated and the results are presented in table 5-20.

Table 5-20 Means and standard deviations, social network circles, all groups (FDA)

	Hypothesis 1				Hypothesis 2			
Variable	**Control**		**All PD**		**Mild**		**Moderate**	
	Mn	**Sd**	**Mn**	**sd**	**Mn**	**sd**	**Mn**	**sd**
Inner circle	8.5	4.5	9.1	6.9	10.7	8.6	7.5	4.4
Middle circle	9.4	6.9	9.4	6.6	11.4	8.1	7.5	4.1
Outer circle	10.2	10.1	11.3	7.8	15.2	8.6	7.6	4.5

It can be seen from table 5-20 that means for circles within the social network do not differ in the manner predicted by Hypothesis 1 because participants with PD have equal or higher numbers of members in each circle of their social network compared with the control group. Means for Mild (FDA) dysarthria are higher than the control group, especially in the outer circle and means for Moderate (FDA) dysarthria are lower, i.e. in the predicted direction (Hypothesis 2). Dispersion of the data in all groups as represented by the standard deviations was very high in all categories indicating a very wide range of sizes for each circle of the network. In order to investigate differences between means and establish whether any statistically significant differences underlay the observed differences in means the data were investigated using multivariate GLM, univariate analysis of variance and post hoc testing.

A multivariate GLM was planned comparing the results for the three circles within the social network, inner, middle and outer. Variables tested using multivariate GLM should be conceptually related but not more than moderately correlated to avoid the problem of multiple collinearity. All of the variables were related to each other as different aspects of social network, however they are not strongly correlated with each other as can be seen from table 5-21 where all correlations are below .5.

Table 5-21 Correlations between social network circles

	Middle	Outer
Inner	.454	.061
Middle		-.136

Box's test for homogeneity of covariance matrices was significant (M=45.5, F= 3.5 (12,19412), p<.001) indicating lack of homogeneity of variance between groups and this was confirmed by Levene's test which was significant and therefore showed unequal variance between groups on the variable 'inner circle'. It was therefore not appropriate to use multivariate GLM as the data did not satisfy the assumptions and univariate analysis of variance was carried out on each variable separately. Levene's test for equality of variance was non-significant for each variable and Kolmogorov-Smirnov tests showed that all data sets were normally distributed with the exception of the inner circle of the All PD group and the outer circle of the control group (see appendix 16). However, as ANOVA is robust to minor violations of normality the procedure was carried out. The results of this analysis are given below:

There was no overall effect of dysarthria severity (FDA) on size of inner circle $F = 1.7$ (2), $p = .19$

There was no overall effect of dysarthria severity (FDA) on size of middle circle $F = 1.96$ (2), $p = .15$

There was an overall effect of dysarthria severity (FDA) on size of outer circle $F = 4.6$ (2), $p = .014$

Planned contrasts were carried out to investigate Hypothesis 1 (Control group with All PD group) and Hypothesis 2 (Mild FDA group with Moderate FDA group). 1-tailed significance values were used because the differences in

means were in the hypothesised direction in all cases. There was no effect of presence of dysarthria (Hypothesis 1) when comparing the control group with the All PD group (all *p* values > .05, 1-tailed). This analysis revealed that there was an effect of dysarthria severity (Hypothesis 2) on size of inner circle $t(70) = -1.80$, $p = .04$ (1 tailed), $r = .21$, middle circle $t(70) = -1.98$, $p = .03$ (1 tailed), $r = .23$ and outer circle, $t(70) = -2.97$, $p = .002$ (1 tailed), $r = .33$. Therefore differences in overall social network size between Mild (FDA) and Moderate (FDA) groups were not related to any specific circle within the network but were distributed across all areas of the network.

Post hoc

Post hoc tests were carried out using the Games-Howell procedure with Bonferroni correction. This confirmed that, despite the higher means in the Mild (FDA) dysarthric group there were no significant differences between the control group and the Mild (FDA) dysarthric group: Inner Circle $p = .53$, Middle Circle $p = .62$, Outer Circle $p = .16$.

Summary

Analysis of the circles within the social networks showed that participants with dysarthria overall did not have fewer members than control participants in either Inner, Middle or Outer circle but participants with moderate dysarthria (FDA) had significantly fewer members than participants with mild dysarthria (FDA) in all three circles. Post hoc testing demonstrated that that participants

with mild dysarthria (FDA) did not have significantly different numbers of members of any of the circles within the network when compared with the control participants.

5.3.10 *Relationships within social network*

Data were collected on the relationship of people within social networks to the participant. Members of the network were classified as being either close family (spouse/partner, child, parent, sibling), other relative, friend or 'other' (not belonging to the other three categories). Mean number of people in each of the categories was calculated and the results are presented in table 5-22.

Table 5-22 Means and standard deviations, relationship categories within social network, all groups (FDA)

	Hypothesis 1				Hypothesis 2			
Variable	**Control**		**All PD**		**Mild**		**Moderate**	
	Mn	**sd**	**Mn**	**sd**	**Mn**	**sd**	**Mn**	**sd**
Close family	3.6	2.5	4.1	1.6	4.5	1.6	3.7	1.5
Other relatives	5.5	4.8	7.1	6.1	9.4	6.8	4.8	4.2
Friends	13.9	11.4	14.3	9.9	18.1	11.8	10.6	5.6
Other	5.6	7.4	4.7	6.2	6.1	8.2	3.4	3.1
Network Total	28.1	13.6	27.3	13.0	37.3	13.3	22.5	8.1

It can be seen from table 5-22 that differences between means for the control group and All PD are not in the direction predicted by Hypothesis 1 i.e. participants in the All PD group had higher numbers in each category of relationship except that of 'other contacts'. This was consistent with results for overall network size. Means in each category for the Mild dysarthric group were

higher than for the Moderate dysarthric group, and these differences were all in the direction predicted by Hypothesis 2.

A multivariate GLM was planned comparing the results for the four categories of relationships within the social network: close family, other relatives, friends and other contacts. Variables tested using multivariate GLM should be conceptually related but not more than moderately correlated to avoid the problem of multiple collinearity. All of the variables were related to each other as different aspects of social network, however they are not strongly correlated with each other as can be seen from table 5-23 where all correlations are below .5.

Table 5-23 Correlations between social network relationship categories (Pearson's *r*)

	Relatives	Friends	Other
Close Family	.273	-.114	-.077
Relatives		.111	.042
Friends			-.117

Box's test for homogeneity of covariance matrices was significant (M=51.5, F=2.355 (20,14671), p=.001) indicating lack of homogeneity of variance between groups and this was confirmed by Levene's test which was significant and therefore showed unequal variance between groups on the variable 'other contacts', $F = 4.35$ (2,70), $p = .02$. Furthermore, Kolmogorov-Smirnov tests showed that distributions were not normal for the All PD group in the variables close family, other relatives and other contacts (see appendix 16). It was therefore not appropriate to use multivariate GLM as the data did not satisfy the

necessary assumptions. Consequently the non-parametric Kruskall-Wallis test was used for comparison of three means with the following results

There was no overall effect of dysarthria severity on number of close family members in the social network $H = 5.66$ (2), $p = .06$

There was an overall effect of dysarthria severity on number of other relatives in the social network $H = 10.01$ (2), $p = .006$

There was no overall effect of dysarthria severity on number of friends in the social network $H = 5.26$ (2), $p = .07$

There was no overall effect of dysarthria severity on number of other contacts in the social network $H = .36$ (2), $p = .84$

Post hoc Mann-Whitney contrasts were carried out to compare the Control group with the All PD group (Hypothesis 1) and the Mild (FDA) group with the Moderate (FDA) group (Hypothesis 2). As two contrasts were carried out, Bonferroni correction for family-wise error rate was applied to the acceptable alpha value, i.e. .05/2 to avoid inflating type 1 error rate. Thus the required *p* value for the contrasts was set at .025.

Comparing the Control and All PD groups (table 5-24) post hoc analysis revealed that there was no effect of presence of dysarthria on any category of relationship.

Table 5-24 Post hoc comparisons for categories of social network relationships, Control and All PD groups

	Close family	Other relatives	Friends	Other contacts
Mann-Whitney U	492.5	543.0	599.5	620.5
Z	-1.75	-1.15	-.51	-.28
***p* (2-tailed)**	.08	.25	.61	.78
Effect r	.27	.18	.08	.04

Comparing the Mild and Moderate (FDA) dysarthric groups (table 5-25) post hoc analysis revealed that there was no effect of severity of dysarthria on number of close family members or number of 'other contacts' within the social network but there was an effect of severity on number of other relatives in the network and number of friends in the social network.

Table 5-25 Post hoc comparisons for categories of social network relationships, Mild (FDA) and Moderate (FDA) groups

	Close family	Other relatives	Friends	Other contacts
Mann-Whitney U	160.0	108.5	136.5	212.5
Z	-1.78	-2.99	-2.30	-.46
***p* (2-tailed)**	.08	<.01	.02	.65
Effect r	.28	.47	.36	.07

.

Summary

Analysis of the categories of relationship within the social networks showed that presence of dysarthria (comparing Control and All PD groups) did not affect numbers in any relationship category. Moderate (FDA) dysarthric participants had significantly fewer relatives within their social network who were outside

their immediate family. Moderate (FDA) dysarthric participants also had significantly fewer friends in their social networks than participants with mild dysarthria. The dispersion of the data in each category of relationship was very high reflecting a very wide range in size of social networks in both participants with no neurological involvement and those with PD.

5.3.11 Social discomfort sub-scales

Social anxiety was measured using the Inventory of Interpersonal Situations Discomfort and Frequency scales. An overall measure of discomfort in social situations was derived from the total for the discomfort scale. However, the scale is also sub-divided in to five sub-scales relating to different kinds of social situation where the participant is involved in: giving criticism, expressing an opinion, giving a compliment, initiating contact and making a positive self-statement (Kraimaat et al. 2002). Results for each sub-scale were recorded and comparisons between groups were made to test the research hypotheses in relation to the effects of dysarthria on social anxiety in specific kinds of social situations. Means and standard deviations for all groups can be seen in table 5-26

Table 5-26 Means and standard deviations for IIS Discomfort sub-scales, all groups (FDA)

	Hypothesis 1				Hypothesis 2			
	Control		All PD		Mild		Moderate	
IIS-D sub-scale	Mn	sd	Mn	sd	Mn	sd	Mn	sd
Criticism	2.51	.76	2.59	.85	2.64	.88	2.54	.85
Opinion	1.92	.59	2.23	.86	2.13	.87	2.31	.86
Compliment	1.32	.35	1.42	.38	1.36	.39	1.47	.38
Initiation	1.41	.32	1.91	.75	1.67	.56	2.14	.84
Positive self-statement	1.78	.51	1.95	.69	1.90	.60	2.00	.77

For each of the sub-scales the research hypotheses would predict greater levels of discomfort in the All PD group compared to the control group (Hypothesis 1) and greater levels of discomfort in the Mild (FDA) dysarthric group compared to the Moderate (FDA) dysarthric group (Hypothesis 2). In general, the means differ in the predicted direction for both sets of comparisons with the exception of the sub-scale 'giving criticism' for Hypothesis 2. In addition, it can be seen from table 5-26 that the means, with the exception of 'Giving Criticism', appear to follow a trend where moderately dysarthric participants reported greatest discomfort, mildly dysarthric participants report less discomfort and control participants reported least discomfort.

These differences were therefore investigated using appropriate statistical techniques.

Multivariate analysis of variance was not attempted because correlations between sub-scale scores were higher than .50 (Pearson's *r*) in a majority of cases and therefore the assumption of independence of variables was violated. In addition, correlations between groups on each sub-scale were highly correlated in the majority of cases which violated the assumption of independence of scores required when using univariate analysis of variance. It was therefore decided to use a non-parametric equivalent, the Kruskal-Wallis test, to test the differences between group scores on each subscale. Results for the Kruskal-Wallis test are shown below.

Giving criticism. There was no effect of group for the Giving Criticism subscale, H (2) = .26, p = .88

Expressing an opinion. There was no effect of group for the Giving Opinion subscale, H (2) =2 .89, p = .24

Giving a compliment. There was no effect of group for the Giving a Compliment subscale, H (2) = 2.79, p = .26

Initiating contact. There was a significant effect of group for the Initiating Contact subscale, H (2) = 13.52 , p = .001

Positive self-statement. There was no effect of group for the Positive Self-statement subscale, H (2) = .99, p = .61

As there was a significant effect for the sub-scale 'initiating contact', post hoc Mann-Whitney tests were carried out to test differences between the groups Control and All PD, Mild and Moderate, in line with the research questions. As two contrasts were carried out, Bonferroni correction for family-wise error rate was applied to the acceptable alpha value, i.e. .05/2. Thus the required p value for the contrasts was set at .025

Table 5-27 Planned contrasts for IIS Discomfort sub-scale 'Initiating Contact'

	U	Z	P (1 tailed)	r
Control – All PD	369	-3.11	.001	.47
Mild- Moderate (FDA)	148	-2.02	.022	.31

It can be seen from table 5-27 that there was a significant effect of presence of dysarthria on level of discomfort associated with initiating social contact (Control- All PD) and there was also a significant effect of severity of dysarthria on level of discomfort associated with initiating social contact (Mild – Moderate) with moderate effect sizes. Furthermore, Jonckheere's test revealed a

significant trend in the data; as severity of dysarthria increased, more social discomfort was felt when initiating social contact with moderate effect size, J = 1235, z = 3.67, p <.001, r = .40

5.3.12 Social avoidance sub-scales

The frequency scale of the Inventory of Interpersonal Situations was also studied using the five subscales: giving criticism, expressing an opinion, giving a compliment, initiating contact and making a positive self-statement. Results for each sub-scale were recorded and comparisons between groups were made to test the research hypotheses in relation to the effects of dysarthria on social avoidance in specific kinds of social situations. Means and standard deviations for all groups can be seen in table 5-28

Table 5-28 Means and standard deviations IIS Frequency sub-scales, all groups (FDA)

	Hypothesis 1				Hypothesis 2			
	Control		All PD		Mild (FDA)		Moderate (FDA)	
IIS-F sub-scale	**Mn**	**sd**	**Mn**	**sd**	**Mn**	**sd**	**Mn**	**sd**
Criticism	2.24	.53	2.27	.53	2.20	.45	2.34	.60
Opinion	2.72	.56	2.78	.57	2.79	.61	2.53	.55
Compliment	3.79	.57	3.56	.74	3.48	.79	3.64	.70
Initiation	3.32	.53	2.96	.71	2.94	.70	2.98	.73
Positive self-statement	3.20	.46	2.94	.63	2.85	.61	3.03	.64

For each of the sub-scales the research hypotheses would predict greater levels of social avoidance in the All PD group compared to the control group and greater levels of social avoidance in the Moderate dysarthric group compared to the Mild dysarthric group. Due to the phrasing of the reporting

form, greater social avoidance is recorded in *lower* scores on the IIS-F i.e. lower frequency of reported engaging in the various social situations. Differences in observed means for these sub-scales are small and in both directions, not consistently in the direction predicted by the research hypotheses. These differences were therefore investigated using appropriate statistical techniques.

Multivariate and univariate analysis of variance was not attempted with parametric tests because correlations between sub-scale scores and between groups were higher than .50 (Pearson's *r*) in a majority of cases and therefore the assumption of independence of variables was violated. It was therefore decided to use a non-parametric Kruskal-Wallis test, to test the differences between group scores on each subscale. Results for the Kruskal-Wallis test are shown below.

Giving criticism. There was no effect of group for the Giving Criticism subscale, H (2) = 2.19, p = .34

Expressing an opinion. There was no effect of group for the Giving Opinion subscale, H (2) =2 .17, p = .92

Giving a compliment. There was no effect of group for the Giving Compliment subscale, H (2) = 2.46, p = .30

Initiating contact. There was an approaching significant effect of group for the Initiating Contact subscale, H (2) = 5,90 , p = .052

Positive self-statement. There was a significant effect of group for the Positive Self-statement subscale, H (2) = 6.60, p = .034

As there was a significant effect for the sub-scale 'positive self-statement' and an approaching significant effect for 'initiating contact', planned contrasts were

carried out using Mann-Whitney tests to investigate differences between the groups Control and All PD, Mild (FDA) and Moderate (FDA), in line with the hypotheses. As two contrasts were carried out, Bonferroni correction for family-wise error rate was applied to the acceptable alpha value, i.e. .05/2. Thus the required *p* value for the contrasts was set at .025. Results are shown in table 5-29

Table 5-29 Planned contrasts for IIS Frequency sub-scales: 'initiating contact' and 'positive self-statement'.

	U	z	P (1 tailed)	r
Initiating Contact				
Control – All PD	430.5	-2.41	.01	.37
Mild- Moderate	218.0	-.32	.75	.05
Positive self-statement				
Control – All PD	437.0	-2.35	.01	.36
Mild- Moderate	185.5	-1.12	.27	.17

It can be seen from Table 5-29 that there was a significant effect of presence of dysarthria (Control- All PD) on avoidance of initiating contact and also on avoidance of positive self-statement with moderate effect sizes. There was no significant effect of severity of dysarthria on avoidance of either social situation. Jonckheere's test revealed a significant trend in the data for both sub-scales: as dysarthria severity (FDA) increased, avoidance of initiating contact increased, $J = 674.5$, $z = -2.06$, $p = .02$ (1 tailed) and avoidance of making positive self-statements increased $J = 713.5$, $z = -1.66$, $p = .05$ (1 tailed)

Summary

Investigation of all subscales within the IIS revealed that underlying the differences in overall scores were significant differences in levels of discomfort experienced when initiating social contacts and avoidance of such situations.

Investigation of sub-scales within the Inventory of Interpersonal Situations Discomfort scale revealed that neither presence nor severity of dysarthria (FDA) significantly affected level of discomfort experienced in social situations where participants were giving criticism, expressing opinions, giving compliments or making positive self-statements. However, both presence and severity of dysarthria significantly impacted levels of discomfort in situations where participants were required to initiate contact with others.

Investigation of sub-scales within the Inventory of Interpersonal Situations Frequency scale revealed that neither presence nor severity of dysarthria (FDA) significantly affected avoidance of social situations where participants were giving criticism, expressing opinions or giving compliments. Presence of dysarthria (FDA) significantly affected avoidance of social situations which involved initiating social contact with others and also making positive self-statements Severity of dysarthria did not significantly impact on avoidance of initiating contact or making positive self-statements.

5.3.13 Satisfaction with participation

A measure of satisfaction with amount of social activity is included in the SOCACT. Participants indicated whether they were (1) satisfied with their amount of activity, (2) desired more or (3) desired less. Only one participant expressed a desire for less activity and so categories (1) and (3) were conflated. Resulting categorical data are shown in table 5-30

Table 5-30 Frequency data: satisfaction with amount of social activity, all groups (FDA)

	Control	All PD	Mild	Moderate
Satisfied	24	16	11	5
Unsatisfied	6	27	10	17

It can be seen from the table that the proportion of participants expressing satisfaction with level of social activity was higher in the control group compared to all participants with PD. There was a significant association of presence/absence of PD with satisfaction, Yates' $\chi^2 = 13.06$, $p = <.001$ (2 tailed), odds ratio = 6.7. Within the group of participants with PD, those with mild speech impairment were evenly split but a larger proportion of those with moderate speech impairment expressed dissatisfaction with social activity level. Further comparisons were carried out to test the significance of the frequency distributions applying a Bonferroni correction which set the acceptable p value at .05/2 = .025. The aim of this was to establish whether severity of speech impairment was associated with lower levels of satisfaction with social activity and to establish whether any difference existed between results for control and mildly impaired participants.

There was a significant association between severity of speech impairment and satisfaction with social activity, Yates' $\chi^2 = 4.04$, $p = .02$ (1 tailed), odds ratio = 3.8. Comparing control participants with mildly speech impaired participants there was a significant association of group with satisfaction, Yates' $\chi^2 = 4.38$, $p = <.02$ (1 tailed), odds ratio = 3.8.

Considering the odds ratio as the effect size for these distributions the results for satisfaction with social activity therefore showed that participants without PD were significantly more likely (over six times more) to be satisfied with social activity than those with PD. The results also showed that mildly speech impaired participants were significantly more likely (approximately 3.5 times as likely) to be satisfied with activity than moderately impaired speakers but equally less likely to be satisfied with activity than control speakers. The results suggest that both presence of PD and severity of speech impairment are associated with lower satisfaction with social activity.

5.4 Summary of Results of Quantitative Data

Data were collected from all participants on four dependent variables which described different aspects of social functioning: number of social activities (SOCACT), number of members of participants' social networks (convoy model), social anxiety (Inventory of Interpersonal Situations Discomfort and Frequency Scales). Data for sub-categories within variables were also recorded. The research questions were investigated by comparing results between combinations of groups:

1. Control participants and all participants with PD (hypothesis 1, presence of dysarthria will affect social functioning negatively)

2. Mildly dysarthric participants and moderately dysarthric participants (hypothesis 2, severity of dysarthria will affect social functioning negatively)

Dysarthric participants were divided into two groups in order to study the effect of severity of dysarthria on social variables. Data were analysed using two methods of dividing the participants: a measure of activity (intelligibility) and a measure of underlying motor speech impairment (FDA). Groups being compared were matched on potential confounding variables both unrelated to PD and related to non-speech aspects of PD.

Intelligibility

Using intelligibility as a measure of dysarthria severity it was found that although group means for the main dependent variables of social activity, social network size, discomfort in social situations and avoidance of social situations differed in the predicted directions there were few statistically significant differences. Multivariate GLM showed no combined effect of the variables. Further analysis for each variable showed that presence of dysarthria negatively affected social discomfort (IIS-D) and social avoidance (IIS-F) and severity of dysarthria negatively affected social avoidance alone. Further investigation of the social anxiety (IIS) sub-scales showed that the sub-scale 'Initiation of Social Contact' was significantly impacted both in terms of increased discomfort and higher avoidance by presence of dysarthria, but not severity of dysarthria. Presence of

dysarthria, but not severity, also negatively affected avoidance of situations involving making positive self-statements.

Motor Speech Impairment

Using a measure of motor speech impairment to divide the dysarthric speakers into higher and lower functioning groups, differences between means for the four main dependent variables were found in the predicted directions, consistent with the research hypotheses. Multiple analysis of variance comparing control, mild and moderate groups revealed that there was a significant main effect of relationship between dependent variables between groups. Univariate analysis of variance revealed that there was a significant main effect on social network size but not on other variables. Planned contrasts and post hoc testing further revealed that presence of dysarthria but not severity affected social anxiety and social avoidance and that severity of dysarthria affected social network size. Further investigation using discriminant function analysis revealed that two functions representing relationships between dependent variables underlay the significant group differences found by the multiple analysis of variance. The first function loaded on social network and activity and differentiated mild from moderate dysarthric participants. The second function loaded on social anxiety and avoidance and differentiated the control group from the participants with PD.

Planned comparisons were carried out to investigate the specific research hypotheses for both the main dependent variables and sub-categories of data within each variable. Significant differences ($p \leq .05$) between groups for both hypotheses and all variables are indicated in table 5-31 below.

Investigation of the four main dependent variables showed that there was a significant effect of presence of dysarthria on social anxiety (IIS-D) and social avoidance (IIS-F) and a significant effect of severity of dysarthria on social network size. There were no differences between groups for numbers of social activity.

Investigation of sub-categories within the main dependent variables was carried out. This revealed that there was an effect of presence of dysarthria on number of leisure activities. Analysis also revealed that there was an effect of severity of dysarthria on number of leisure activities. In addition, number of formal social group activities, cumulative monthly frequency of activities, number of relatives in the social network and number of friends in the social network were also significantly affected by severity of dysarthria. Further investigation of social anxiety measures revealed that there was a significant effect of both presence and severity of dysarthria on the extent of discomfort that participants felt when initiating social contact. Presence of dysarthria, but not severity, significantly affected avoidance of social situations that involved initiating contact and also making positive statements about themselves in social situations.

From table 5-31 it can be seen that, overall for this sample, social variables were more sensitive to the differences in measure of motor speech impairment than measure of speech intelligibility. Variables that are more sensitive to presence of motor speech impairment (Hypothesis1) are associated with social anxiety and avoidance whereas variables that are more sensitive to severity of motor speech impairment (Hypothesis 2) are associated with social activity and social network. Effect sizes are small-moderate but consistent, with the largest effect sizes evident in the social anxiety scales suggesting that this measure is more sensitive to variation in severity of dysarthria than the measures of social activity and network.

Table 5-31 Summary of group comparisons of dependent variables showing differences between groups at $p \leq .05$

✓signifies group differences in means are in predicted direction, p≤ .05

Variable	Hypothesis 1 Presence of dysarthria Control- All PD	Hypothesis 2 Mild – Moderate *Intelligibility*	Hypothesis 2 Mild – Moderate *Motor speech imp.*
Social Activity	-	-	-
Social Network	-	-	✓ (*r* = .38)
Social Anxiety (IIS-Discomfort)	✓ (*r* = .24)	-	-
Social Anxiety (IIS-Frequency)	✓ (*r* = .20)	✓(*r* = .23)	-
Activity			
Leisure	✓(*r* = .28)	-	✓(*r* = .21)
Informal	-	-	-
Formal	-	-	✓(*r* = .25)
Frequency	-	✓(*r* = .22)	✓(*r* = .43)
Network			
Inner circle	-	-	✓(*r* = .21)
Middle circle	-	-	✓(*r* = .23)
Outer circle	-	-	✓(*r* = .33)
Close family	-	-	-
Other relatives	-	-	✓(*r* = .47)
Friends	-	-	✓(*r* = .36)
Other contacts	-	-	-
IIS-D			
Criticism	-	-	-
Opinion	-	-	-
Compliment	-	-	-
Initiation	✓ (*r* = .47)	-	✓(*r* = .31)
Pos. self statement	-		-
IIS-F			
Criticism	-	-	-
Opinion	-	-	-
Compliment	-	-	-
Initiation	✓(*r* = .37)	-	-
Positive self statement	✓(*r* = .36)	-	-
Satisfaction with activity	✓ (odds ratio 6.7)		✓ (odds ratio 3.8)

6 Chapter 6 Qualitative Investigation

6.1 Introduction: the approach to qualitative data collection

The qualitative aspect of this project aimed to understand the individual experience of speakers with dysarthria in relation to how they understood their social lives to be impacted by living with Parkinson's disease and speech impairment. It was intended as a supplement to the quantitative methods used to address the related research hypotheses stated above and to provide a means of understanding those results which took account of the perspective of the research participants as well as the researcher. A suitable approach to accessing this kind of meaning is through thematic analysis of the accounts of participants which focus on the individual experience and a method of obtaining such data is that of in-depth interviewing. Two important considerations which apply when considering a qualitative research strategy are whether the chosen strategy will generate sufficient and suitable information and whether the approach to data collection is efficient (Marshall and Rossman, 2006). Interviews are informationally productive and in this study were combined with the quantitative data gathering. Therefore the method was resource efficient from the point of view of both researcher and participants as interviews could be conducted at participants' convenience.

There are a number of assumptions implicit in adopting an interview approach for data collection. One assumption is that participants' accounts of their experiences will be accurate. A second is that the researcher will be able to

construct a valid interpretation of the data. Both of these assumptions must be acknowledged by the researcher and the methods of data gathering and data analysis must embrace techniques which take account of them.

Interviews were semi-structured in order to allow participants to influence the ways in which topics were developed. Data collection through interviewing was guided by the precept that the participant's perspective should be allowed to be expressed as the participant views it. A variety of techniques were employed to achieve this aim. During the interviews the researcher and participants negotiated meanings at certain points in order to arrive at a shared understanding of the underlying experience that the participant was describing. An example of this clarification process which helped researcher and participant to share what was meant by 'non-motor things' occurred

P37:... overall is the fact that (...) the non-motor things(....) have been worse than the motor things for me to accept.

Int: What sort of things are you thinking of?

P37: (erm (.) things that I wouldn't go out and I was depressed when I was first I was first off I was depressed 'cos I've always been not being funny I've always been to work

Other features of data collection which were designed to support the accuracy of the participants' contributions included methods to ensure that the participants were comfortable in the interview. The researcher made use of techniques such as mirroring non-verbal communication to support rapport building and was sensitive to non-verbal signals which indicated that

participants had more to say. Working with this group of participants it was necessary to be sensitive to the impact of their communication impairments on the interaction. The researcher had considerable experience of conducting assessments with people who had neurogenic communication impairments and was able to use this experience to support the process of interviewing for research purposes. For example, pausing behaviour in interviews is important because pauses can be taken as indicators that the participant may have more to say or an interlocutor may attribute a specific meaning from the speaker's pause (Steven Bloch & Wilkinson, 2009; Lesser & Milroy, 1993). It is advisable when in conversation with communication-impaired populations to give the participants more time than would be given in normal conversation and accept longer unfilled pauses (Legard, Keegan, & Ward, 2003). Symptoms of dysarthria in Parkinson's disease include dysfluencies and difficulties initiating speech movements which should be taken into account in addition to the general need when interviewing to allow the pace of the speaking to be determined by the participant. Therefore both pace of interview and management of interactional behaviour were necessary in order to ensure that participants were able to express everything they had to say and, by sensitive handling of pauses, that the complete account was not lost, e.g. in this account the participant, given time to expand on her first response, provided an explanation of why she did not go on holiday and also an account of the wider impact of PD

Int: Do you think that you would have had a holiday if you hadn't had Parkinson's?

P51: Probably (...) yes (1..) but I I know my daughters don't want to go with me and I don't blame them I don't blame them (...) but (.) it's things like that that now and again (..) sort of (1..) make you realise what you've got.

In order to engage with the participants, interviews should be conducted in a tone that encourages them to speak freely. The researcher endeavoured to be sensitive toward the participants and facilitate the relationship with them through supportive responses which maintained the flow of the interview and encouraged trust, e.g.

P37: you know it might seem silly to you but

Int: No I can quite understand

P37: but <um> and <um> and I felt (.) I felt (.) I felt terrible and that sort of thing (..) and <um> (...) <um> that's been my worst thing at all of anything really

The questioning of the participants during the interview was structured to draw out the participants' experiences of social change and perceptions of the causes of change in more depth by using ground mapping questions and probes and these are presented in section 6.3.2 below.

6.2 Method of data collection

6.2.1 Participants

All participants involved in the project provided interview data for analysis. Qualitative research using in-depth interviews may use purposive sampling in order to target a key constituency but it is important to maintain diversity within the sample (Ritchie, Lewis, & Elam, 2003). For this study it was felt that it was advantageous to collect and analyse data from all participants who contributed to the quantitative data collection for several reasons: to avoid any bias in participant selection from that population which might have resulted in a narrative overly-influenced by the researcher's own preoccupations; to ensure that the qualitative analysis meaningfully explored the full range of participants' views; to ensure that interpretations based on both quantitative and qualitative data referred to the same participants. Participants were people with a diagnosis of PD and who reported changes to their communication of different levels of severity. The mean age of participants was 69.1 years (s.d. 8.9) with age range between 53 and 84 (N = 43). There were 28 male and 15 female participants. 41 participants belonged to socioeconomic class C1 or C2 and only 11 participants completed any education beyond the age of 18. Further details of participants can be found in section 3.4.4

6.2.2 Interview questions

A list of topics was used to guide the interviews towards addressing the research questions and to ensure some degree of equity between transcripts. Data were collected using questions which were developed to address the

research question and to accommodate the research philosophy described earlier. Wording of questions was guided by Legard et al's (2003) framework for achieving breadth and depth in interviews. A key aspect of this is the distinction between content mapping questions and content mining questions, that is, questions which open up a topic and questions that explore the content that the interviewee has raised. Content mapping questions raise an issue that is of interest to the interviewer, content mining questions aim to reveal the meaning that it has to the participant. Content mining often occurs through probe questions which follow up issue that have been raised by the interviewee and may achieve depth through amplification, explanation and clarification (Legard et al., 2003). Through use of probe questions the researcher was able to draw out more detailed description and explanation of topics from participants. For example, an issue of central interest was to establish whether participants believed that changes had taken place in their social lives since the onset of PD and this was mapped with questions such as,

'Do you think that your social life has changed at all since your diagnosis?'

Often, participants interpreted this as an invitation to describe how things had changed in their social life and began to provide details of this. Some participants offered a minimal response to the question and this was then followed up by a probe for greater amplification e.g.

'Could you tell me a bit more about that?'

At points in the data where participants raised a topic of interest themselves further amplification was necessary and at these points the researcher followed up with an amplificatory probe e.g.

P37:.. .overall is the fact that (...) the non-motor things(....) have been worse than the motor things for me to accept.

Int: What sort of things are you thinking of?

(P44)

Int: So when you say they make allowances, how do they express that?

Content mapping was also suggested by issues raised by the participants themselves which could be followed up by probe questions e.g.

Int: You mentioned that your speech has been affected.

P11: Yes it definitely has.

Int: How has it changed?

The researcher also used probes to seek explanations of their experiences from the participants e.g.

(P10) Int: What do you think caused the change in social activities?

(P64) Int: And can you say why you are reluctant to talk?

The interview is a collaborative attempt to recover meaning and so there are many points at which interviewer and participant must do work to achieve a

shared understanding. Probe questions often seek clarification of meaning and language and demonstrate the interviewer's commitment to listening e.g.

(P35) Int: 'It's interesting.' What did you mean by that?
(P59) Int: What do you mean by 'think clearly'?

Working with people with dysarthria, clarification was also needed where the interviewer had failed to understand the speech rather than the meaning of the participant. It was important for the researcher to seek clarification at these points both to show respect to the participants (communication impaired speakers prefer interlocutors to acknowledge moments when they have not understood (Bloch and Wilkinson, 2009; Booth and Perkins, 1999; Connect, 2013; UCL, 2013)) and to ensure that the full meaning of what the participants had to say was recoverable on later listening. For example, in this exchange, the precise choice of vocabulary by the participant clearly expressed something significant to her,

P10: They think I'm a (2 syllables, unintelligible)
Int: They think you're a..?
P10: Cretin

The questions were designed to allow the participants freedom to recount and explain any phenomena relating to the impact of PD on their social life and to avoid giving any aspect of PD pre-eminence in those explanations. Each

participant was interviewed once because that provided sufficient opportunity to gather appropriate data to address the research questions and because ethical approval had been granted for single interviews.

Further techniques were employed during content mining questioning for gaining depth from participants' responses. These included demonstrating to participants that the researcher was genuinely listening. For example, where it was relevant to the research questions the researcher recalled points that the participant had made earlier in the interview for further elaboration, demonstrating that he was actively listening to the speaker's account.

Int: So you said that your social life has changed.
P11: Oh yeah. I'm not doing as near as much now.

Int: You say you're more cautious about dining out.
P43: Well it's difficult at times to (erm) swallow.

The researcher also provided reassurance that the accounts that the participants gave were of value in their own right in order to encourage them to provide accounts that truly reflected their own experience rather than attempting to fit accounts to what they considered to be the researcher's expectations.

P37: I hope I'm answering these questions okay for you.
Int: Yes, that's fine. There's not a set answer

Another technique to help maintain the authenticity of the accounts was to use the participants' own language, so validating the participants' perspectives and avoiding placing a top-down interpretation on the phenomena being described. For example, when P51 referred to a motor impairment she used her own term which the researcher invited her to explain by using it in his response.

(P51) Int: You've noticed a change in that and you call it a 'wobbly'

6.2.3 Procedure

Conduct of Interviews

Interviews took place in a location of the participant's choosing, where they indicated they would feel most comfortable and at a time of day when they indicated they would be optimally medicated. The interviews were arranged at the start of the data collection process, before any assessments of speech or other aspects of PD were made, in order to avoid prejudicing the participants' responses.

Recording

Recordings were made using a Marantz PMD670 solid state digital recorder with a sampling frequency of 44.1kHz and a recording bit rate of 128kbps, linked to a an AEG C 444L head mounted condenser microphone with 9 volt power supply positioned a constant 2cm from the participant's mouth. The microphone is a pre-polarised condenser cardioid microphone with a frequency

range of 20-20,000Hz. Recordings were stored as .wav files on a Toshiba laptop computer and for transcription were played back through Sony DR-220 headphones.

6.2.4 Ethical issues

All participants were given written information at least one week prior to data collection which detailed their involvement. They were also given an opportunity to ask any questions of the researcher prior to data collection and it was reiterated that their participation was voluntary and they were free to withdraw at any time. All participants signed consent for audio recording and data analysis as part of the project. For full details of ethical procedures see section 3.4.6

6.3 Thematic analysis

In this section the approach to data analysis is set out and then described in detail. This includes the stages of analysis: coding the data, organising the data in themes and sub-themes, exploring the relationships between aspects of the data and generating a theoretical structure. The focus of the analysis was to provide an 'insider perspective' on experiences which underlay the quantitative data gathered on social network, activity and anxiety.

6.3.1 Handling transcription data

Recordings of interviews were transcribed verbatim orthographically. There are no set conventions for transcription applicable when thematic analysis is being undertaken (Braun and Clarke, 2006), unlike other more specific forms of

transcription, such as that used for conversational analysis, which require detailed conventions to express the fine detail of the interaction. For consistency the researcher followed conventions for orthographic transcription (Tagliamonte, 2004) with additions to accommodate detail of pausing behaviour, dysfluency and sections of unintelligible speech. The most important aspect of transcription is that it is accurate to the verbal content of the recording and true to the meaning. Therefore, punctuation was not added to the transcripts but filled and unfilled pauses were included. All filled pauses were marked in the transcripts as <erm> irrespective of the phonetic realisation of the fill. Unfilled pauses were marked using the following conventions:

pauses up to one second in length were rounded up to the quarter second and marked with periods within parentheses e.g. (.) signifies a pause of up to 0.25s, (..) signifies a pause of up to 0.5s. Pauses over one second in length were marked with the number of complete seconds plus period marks signifying quarter seconds as above e.g. (2...) signifies a pause of 2.75 seconds.

A sample of three transcriptions was checked for accuracy. The recordings were transcribed by a second listener who was not familiar with dysarthric speech following the same protocol as the first listener. Where differences were noted between transcripts these were discussed by both listeners

Thematic Analysis

Transcriptions were created in MSWord and then imported into NVivo with unique identifiers into a single ‘project’ which allowed coding of the texts and creation of nodes and memos.

Thematic analysis is a commonly used approach to the analysis of interview data which offers the possibility of both recovering meaning from the experiences described - as (Van Manen, 2011) puts it, an opportunity to ‘get at’ the phenomenon of interest - , and at the same time thematic analysis gives order and control to the process of writing about the phenomenon. Themes are the result of searching for repeating ideas in the textual data in a systematic way. An advantage of thematic analysis is that it can be applied across a range of theoretical approaches to qualitative researching and is itself not bound to a particular epistemological position unlike, for example, grounded theory, and is thus suitable for a mixed methods approach where the epistemological position of the researcher is neither purely realist nor purely constructivist. It is necessary to acknowledge the inevitably active role that the researcher plays when carrying out thematic analysis and that themes do not simply emerge from data without some selection and interpretation by the researcher (Braun and Clark, 2006). Within themes, as data accrues, it may be possible to see sub-themes which capture some more specific aspect of the wider theme (Braun and Clarke, 2006)

6.3.2 Nodes

Free nodes where appropriate during analysis were organised within tree nodes. Working through the texts individually each piece of data was scrutinised and as new ideas appeared new nodes were created. Where a piece of text reflected an existing node the relevant section was added to the existing node and this process continued throughout all of the transcriptions until a list of all nodes had been created. The result of this was that for any node all the sections of text relating to that node could be called up in a single document. During this process the researcher was aware of the interpretative process occurring and this awareness is reflected in the creation of memos which contain observations about the data and about the analytic process. For example, at certain points, as text was coded to an existing node it became apparent to the researcher that the contents of the node represented more than one node and needed to be split. An example of the process of redefining of nodes which emerged from this stage of analysis was that the early node 'Speech change in PD' was found to contain data items that were all accounted for more precisely in other nodes. Thus an individual data item from within this node, '...can't make myself understood any more' was combined with data relating to the node 'Speech Intelligibility' and this node in turn was recombined with various nodes into a single node 'Speech Change' .An example of the recombination of nodes can be seen below where the nodes

- Parkinson's self-conscious about appearance
- Mobility perception of others
- Concealing your PD

- Parkinson's impact on self image

were recombined into a single node

- Self-conscious about how presents

6.3.3 Reflexivity and Bracketing

While the rigour with which qualitative research is carried out can help to make findings more robust, approaches to understanding phenomena through the accounts of participants, such as thematic analysis, are unavoidably subjective since the analysis takes place through the researcher who brings to the analytic process theoretical preconceptions, values and beliefs. If these remain unacknowledged, the interpretation of the data will be coloured but the reader will be unaware of the filters that are tinting the interpretations. A technique developed in phenomenological inquiry to mitigate this is 'bracketing' whereby such preconceptions regarding the research process are acknowledged by the researcher as a means of controlling their influence and reducing bias. The roots of bracketing are in the phenomenological attempt to get to the direct seeing of phenomena, that is, phenomena unmitigated by the preconceptions of the researcher (Tufford and Newman, 2012). However, some researchers have rejected the notion that this is truly possible and regard the researcher's position as inherently subjective (Heidegger, 1967).

While the latter position may be appropriate to certain qualitative research methods e.g. participatory action research where engagement of both the researcher and the participants together throughout the research process is central to the goals of research, this was not the goal of the present study where the epistemological position of the researcher is one of critical realism. Bracketing is a reflexive process whereby the researcher, in turning a light on himself, aims to recognise that he is part of the social world that is being studied, not separate from it. It was appropriate, therefore, to attempt to acknowledge social, cultural and personal preconceptions that the researcher may have brought to the research process and this is done here, following Ahern (1999).

Acknowledging the researcher's identity

The interests of the researcher may unconsciously bias research activity. By reflecting on these interests and declaring them the researcher was being reflexive towards the process of analysis to identify how they may have influenced the process. Participants were informed that the researcher has a professional background as a clinical speech and language therapist working within the public sector and as a lecturer in speech and language therapy. Also, they were informed that this project was being completed as part of a PhD and that the results would be disseminated to the participants and might be published more widely. This information may have influenced the participants in different ways. It is possible that the researcher's professional background

enabled them to form beliefs about motivations for and benefits of the study and a number of participants expressed the view that their participation was based on a desire to, in some way, 'help'' to advance understanding of PD. The researcher's race, gender and socioeconomic status (white, male, university lecturer) were evident to participants, the researcher dressed and behaved professionally towards participants and this is reported because aspects of cultural identity may give rise to projections on to the data (Ahern, 1999).

Acknowledging the influence of the literature

The literature reviewed in chapter 2 formed a preparation for the analysis of the participants' accounts. Qualitative data analysis does not rely on testing existing theory and detailed reviewing of literature may even take place after data analysis (Ahern, 1999). However, in mixed methods research which follows the model used in this project it is not possible to formulate appropriate research questions and devise a methodology without prior knowledge of relevant literature. It is therefore acknowledged that the literature identified in chapter 2 influenced all stages of the research process.

Reflexivity in the research process

Thematic analysis is a process which involves frequent reengagement with the data. Analysis is iterative, the data being scrutinised many times in order to produce an interpretation. This revisiting encourages reflective analysis but it is also important to be reflexive in relation to the process itself, for example to

recognise where discovery of new meanings has ceased and to challenge the basis of this in order to identify whether this is due to interpretative saturation or that the researcher is too close to the data and has become blocked or desensitised (Ahern, 1999). During the process of analysis the researcher frequently stepped away from the computer-based analysis of text or used alternative means such as pen and paper to work with more graphic representations of concepts in order to avoid these pitfalls. This enabled the researcher to build the thematic structure and then test the ideas against the data when he reengaged with the transcriptions again.

Memos were written as part of the documentation of the research process to make transparent thoughts about the ongoing analysis and how interpretations of the data evolved. Memos captured both decisions made and influences leading to decisions and through these memos the researcher was able to bring to the surface aspects which shaped the outcome of analysis and to recognise these at a later stage. The memos also recorded ways in which the researcher challenged the interpretations that had been placed on the data. (Memos are reproduced unedited)

> 20/1/13
> The first stage of coding was maximally detailed to ensure that all participants were represented. The next stage is to consolidate similar and related data. To do this I am creating parent nodes into which putatively related data can be dropped. E.g. the first of these is 'Speech change motoric' which aggregates data relating to speech production changes but not to the impact of these. This node includes changes to volume, articulation, intonation and fluency but not intelligibility or communicative effectiveness. I will have to challenge this grouping later to check the validity of the concept and its loyalty to the data. I chose this

grouping first because such speech changes seem relatively easy to identify.

13/4/13 memo linked to node ‘speech change motoric’
having integrated Parkinson's disease speech change into this node I must evaluate the underlying content - is this a single node. Also, how do other nodes, such as speech voice quality, speech articulation, speech volume, speech dysfluency and speech intelligibility relate to this node?

As analysis proceeded, more abstract concepts became part of the thematic structure. The process involved iterative checking of concepts against the data and the way that the researcher raised questions and introduced ideas in relation to existing conceptualisations of the data was recorded.

18/6/13
The volume of data relating to the impact of speech change is much higher than that relating to the changes to motor speech itself although the number of sources is very similar. what does this suggest about how people respond to changes to their speech? It might suggest that communication is of high importance or that they are aware of a range of ways in which life can be impacted by a change.

Reflexivity was demonstrated in the conduct of the research by identifying the ways in which the researcher both helped to produce as well as construct the findings. Re-reading the interviews the researcher noted that he was active in managing interactions to achieve the research goals. For example, where appropriate, a more conversational interaction was temporarily adopted, taking the lead from the participant, in order to deepen the engagement between researcher and participant.

P7: Not yet no (....) no (3s) Made it clear the other night when the earthquake happened. That certainly made it clear (laughs)

Int: Yes you might have said one or two things then (laughs). Yeah that was a shock wasn't it?

P7: wasn't it just.

Int: It's a bit unusual (..) nobody'll ever (...) in this area

P7: That's right. They had one at <name of town> a few years ago. That's not far from here and that one it's nearer than <name of city> actually where this one happened (..) it <um>

The following is an example of how the researcher attempted to achieve reflexive neutrality during an interview. In this case, expectations about the researcher's preconceptions were mitigated as the participant was giving the account.

P37: I hope I'm answering these questions okay for you.

Int: Yes, that's fine. There's not a set answer

The researcher used bracketing and reflexivity to try to reduce the effects of subjectivity in the analysis. However, ultimately it is acknowledged that what results is one interpretation, albeit one that can be challenged with reference to the data because it was arrived at by a reflexive process that was both transparent and loyal to the data.

6.3.4 Themes

Initial reading and rereading of the transcripts of the interviews enabled the researcher to identify repeating patterns of thoughts and ideas in the data. Themes are what are identified as patterned responses which have relevance to the research question and so represent units of meaning within the data corpus (Cohen et al,. 2007). As the interviews focused on particular aspects of the participants' experience, namely the changes to social life consequent on PD, the aim of analysis was to provide a rich description of the entire data corpus rather than a detailed account of a particular aspect or individual. The approach to coding data was inductive, or data driven, as the researcher aimed to make themes link strongly to the data without consciously imposing a theoretical position or preconceptions on them a priori. In order to do this the researcher aimed to 'bracket' previous assumptions allow himself to be open about the phenomena being described. Bracketing is a process used in the field of phenomenology to take account of the cultural influences that researchers bring to the research process (Finlay, 2008). In this study it was not possible during analysis to arrive at a completely undistorted view of the data, what phenomenologists would consider 'direct and primitive contact' with the data (Groenewald, 2004 p18) as analysis of the quantitative data had already taken place and some conclusions had been drawn about what that data did and did not communicate about the research questions. However, it was important to be able to acknowledge this state of knowing about the data in order to be reflexive during analysis and to be open to new meanings.

6.3.5 Stages of analysis

Data analysis occurred in various stages: during familiarisation with the data, during coding of the data, during development of the thematic structure and during development of theoretical constructs.

First, during recording and more definitely during transcription and proof reading, the researcher began the process of familiarisation with the data. This was supplemented by careful re-reading of the finished transcripts. Familiarisation is an essential phase for understanding the data, akin to 'building the foundation of the structure' (Ritchie, Spencer et al,. 2003 p231). However, while Ritchie, Spencer et al (2003) advocate the use of familiarisation for creation of an explicit conceptual framework before data is coded in detail, this researcher adopted a more data-grounded approach to the development of the conceptual framework. That is to say, data were coded in detail before a conceptual framework was committed to paper. This approach was taken in order to acknowledge the risk of categorising data according to the researcher's preconceptions and assumptions rather than being true to the meanings actually being expressed. However, it is important to acknowledge that the conceptual framework that the researcher brings to the project can never be fully expunged and so the process of coding is necessarily interpretative to a certain extent.

More explicit analysis took place in stages of varying concreteness and abstraction in relation to the data. Descriptive coding is the process of initial coding which focuses on studying each section of text and deciding 'what is this

about?' (Ritchie, Spencer et al, 2003 p224), identifying what the subject of each section of the data is and assigning it in NVivo to a 'node'. At this stage the researcher aimed to identify a very wide range of nodes. Each transcript was read and studied individually and passages were coded for meanings that related to some aspect of the research questions. At this stage, relevance was treated very broadly so as not to exclude data that might appear more relevant at a later stage of analysis. Passages that were coded for meaning varied in size down to single short utterances depending on the researcher's interpretation of their meaning and relevance. By coding these passages as new nodes or by adding them to existing nodes within NVivo the data were managed and organised in a way that facilitated further analysis. The coding did not follow a prescribed pattern but was guided by the text of the transcripts.

The first list of nodes created from the data set was large (161 separate nodes). This was important in order to capture the breadth of meaning in the data and to ensure that the detail of the range of experiences and perceptions in the sample as a whole was represented.

From the initial large number of nodes the next stage of analysis was to review and consolidate the node list to identify candidate categories which represented groupings of nodes where separate nodes appeared to reflect similar underlying meanings. This process resulted in the creation of new nodes which incorporated data from separate nodes, reducing the overall number of nodes

and increasing the level of abstraction which they represented (see example below, table 6-1).

Table 6-1Table 1 Examples of 'tree' nodes

Response to PD
Controlling change
Accepting change
Support from others
Help from others
Communication easier with older people
Provision of adaptions
Independence
Dependence on others
Others limit activity

Each time this process of review and consolidation occurred was an interpretation of the data and this process formed part of the reflexive engagement with the data necessary to ensure accuracy. Names of nodes were revised during this consolidation period to encapsulate the meaning of all the data contained in the node. The prevalence of nodes can be examined in NVivo which records both the number of data items within the node and the number of sources from which the data come. Following the process of node system consolidation it is therefore possible to see those nodes which represent data from only one or two participants and which may therefore be 'outliers' or not contain meanings which are essential to the data set. In this study prevalence is indicated in the language used such that 'a majority of participants' indicates where data come from more than 75% of sources, 'many participants' signifies 50-75% of participants and 'some participants' signifies between approximately

25% and 50% of participants. Those merged nodes which contained data from a minimum of 8 participants were considered to be most important for further analysis (Greenstock, 2009). The result of the process of consolidation was a list of nodes which could be considered as candidate categories or potential themes on the basis of both relevance to the research questions and prevalence within the data set. A final list of consolidated nodes in which earlier nodes were grouped was generated and this list formed the list of candidate categories (table 6-2)-:

Table 6-2 Candidate Categories

Acceptance by others
Confidence
Impact of speech change
Independence
Motor speech change
Parkinson's emotional impact
Parkinson's impact on cognition
Physical symptoms
Reactions of others
Attitude to PD
Self-consciousness about public face
Social life changed
Social life positive
Social life range
Support from others
Symptom variation

Categories were then tested against the data by recoding with these categories in mind in order to see if the categories were robust and those categories which continued to fit the data were adopted as emergent themes. An advantage of using NVivo is that pieces of data can be stored electronically within nodes

without removing them from their textual context in the original source document. It is therefore very easy to review any section of text in its original context in the light of developments in the node system (and later in the conceptual map) with less risk of loss fidelity to the text than if data were physically separated in the process of coding. At this point the researcher was examining the coherence between different pieces of data within a category looking for repeating ideas. Those pieces of data which did not fit the pattern were considered for removal from the category with various possibilities for action: to allocate to a different category, to create a new category, to discard as not relevant to the research questions. As the node list was reviewed against the data, distinctions between existing nodes were challenged by the researcher and recombined, as in the examples given above (page 223)

Where patterns of data within categories were established as coherent and appeared significant to the research questions these were adopted as themes:

- Changes to speech
- Changes to social life
- Accounts of how PD impacts social life
- Participants' response to PD

Both themes and sub-themes were identified through this process. The themes appeared to represent the key ideas present in the data. Relationships between themes were considered in order to understand any hierarchical relationships which were evident and to identify any more abstract concepts which underlay

the data and which were represented by over-arching ideas or labels for groups of themes. This process of refinement included identifying sub-themes within themes and considering the relationships between these sub-themes. The developed thematic analysis formed a conceptual map of the data. The process of reviewing the data and the thematic map is iterative and was continued until a satisfactory thematic map was arrived at which represented the data as a whole. This thematic map was then further investigated in order to see if any underlying theoretical constructs emerged which could account for relationships between and within themes. This is presented in the following chapter.

7 Chapter 7 Results of Qualitative Investigation

7.1 Introduction to chapter

In this chapter the thematic analysis is presented. Four main themes emerged from the data; changes to social life, speech changes, accounts of how PD impacts social life and participants' responses to PD. These themes are explored and data is presented in the form of excerpts from the interview transcripts to evidence claims. Each data excerpt references the source of the data using the identifying number of the participant and further demographic information about participants can be found in table 3-3. The themes and sub-themes have many inter-relationships which are discussed towards the end of the chapter where a theoretical explanation of the data is also presented to account for the data at a more abstract level.

In this chapter, some reference to relevant literature is made where appropriate but a full discussion of the results in relation to the theoretical context is in the following chapter where quantitative and qualitative findings are integrated.

7.2 Theme 1 Changes to social life

As a result of examining the data it was found that a clearer thematic structure was emerging from the accounts of change to social lives. A sub-theme was identified focussing on change relating to quantity of activity including accounts of how quantity and frequency of activity and contacts has decreased, how particular activities and contacts have been lost and also how new activities and contacts have been gained. Within this sub-theme there is also some indication

of how the nature or quality of activities has changed. There is another sub-theme focussing on continuity, in which accounts speak of maintenance of social life, continuation of particular activities and the importance of family and friends within their social lives. This interplay between transformation and continuity is recognised in other investigations of life with chronic illness (e.g. Kralik, 2002)

7.2.1 Sub-theme (a) Loss of social activity

It is useful to start with the recognition that the impact of PD on social life can be profound and wide-ranging.

P8 But since getting Parkinson's it's altered completely my way of life you know. Social life and everything.

Some participants referred to a general reduction in the quantity of social activity in comparison with their experience prior to diagnosis.

P11 I'm not doing as near as much now
I mean one time we were here there and everywhere but now

P36 Well <um> I (..) well I don't socialise as much anyway

P5 Well (...) well we haven't got as much of a social life these days I must admit (..)

P6 I stay in a lot but I do get to go out quite a bit (...) when I can.
Int: Do you go out much with your wife?
P6: Not as much as we used to no

Providing more detail about the nature of the reduction or change in social life, many participants referred to specific activities that were no longer carried out.

A range of types of activity were affected. Sometimes communication was a central concern associated with the loss of the activity e.g. giving up voluntary work for the Samaritans and not having people round to the house for meals. Sometimes the greatest obstacle was that of mobility and an issue which was important for many was where an activity depended on the ability to travel, either using their car or public transport as both types presented physical challenges. This affected visits to family, leisure trips and holidays. Related to this was the effect of physical limitations on particular activities such as bowling, cycling and swimming which depended on a minimum level of mobility.

P40 Well I would think <um> (..) nothing of just getting on the train going to London (^..) going to a new show

P64 There are lots of things I don't do (1..) I go to tai chi (laughs) (erm) but we used to go up to London quite a lot but we haven't done that for ages (3.0)

P63 P: I don't walk as much as I used to. I used to like walking but I don't do that so much these days. It's too tiring (..) can't do that

P5 but I used to be (cough) very fit. I was very fit for my age. I used to go swimming every week and I still worked up till (.)

It is also interesting that in these accounts there is a contrast between activity prior to onset of disease and the more restricted set of activities that can be managed in the present because of their illness and there is discursive work taking place by the participants to present themselves as ill rather than, for example, lazy.

A feature of change in social life that emerged was that the picture was complex when looked at on an individual basis. An example of this is seen in the account of P60 who demonstrated the points made above, reporting both a general reduction in social activity and the loss of a particular activity. However, although he was conscious of going out less, which he attributed to increased fatigue, he also asserted that he maintains activities he enjoys. Probed on this he referred only to the more solitary activities of 'pottering about' and reading. It seems unlikely that he has given up only those things he didn't really enjoy, as he first claims. In fact the one activity he does describe as having given up was training a youth football team and he was sufficiently motivated by this activity to continue the social connection by going to watch the team play. So in P60's account there have been significant changes in his social activity, including activity loss, but these have also been construed as continuation of activity within his wider social life.

P60 (erm) well I don't go out so much as I used to. I still do the things I like to I enjoy doing.

you know my social life I mean I'm not as active as I was but (er) I still I don't (unintell) as much but I suppose I'm not trying I'm not I get a bit tired.

Well the thing I did give up was I used to help look after some young lads you know from a football team but (er) I still go and watch them occasionally but (er)

but (erm) no it's difficult really 'cos I I I I mean many people say 'What do you do? Do you get fed up?' well I potter about and i do read quite a lot.

In fact, a number of those who reported loss of activity or contact also reported acquiring new activities or contacts suggesting that social life with PD and

dysarthria is not one of inevitable decline but it is important to look closely at the profile of activity and how that is changing, not just the overall level.

P53 As far as the physical activity's concerned probably increased but the social networking as call it is is (..) not so much (..)

There were examples of how participants had recognised the limitations that PD imposed and had adapted to them, for example for P37 accepting that trips away were now easier in organised groups. Whilst such groups were a benefit on a practical level this sometimes entailed some adjustment of self-image; coming to terms with having more in common with a group that he previously felt differentiated from. In addition, although participants might not have registered a change in the overall volume of social activity PD could alter the background level of comfort to social interaction by taking away the ease that was formerly felt in social situations.

P37 well (.) I mean (..) would you believe (.) if you'd told me a few years ago (...) that <um> I wouldn't go on (.) you know wrinkly tours and that

P38 So you're not quite as relaxed about it but (.) no I wouldn't say it made a great deal of difference.

In summary, participants delineated changes both to the overall extent of social activity and to specific activities and in doing so they articulated a view of their current pattern of activity as determined by their illness. However, the picture was not necessarily one of inevitable contraction of social activity. Some participants reported acquisition of new activities or new ways of pursuing existing interests. In this process, changes to sense of social self became an issue to be confronted.

7.2.2 Sub-theme (b) New Activity or Contacts

There was evidence in the accounts that some participants had, since diagnosis, gained new social activities and new social contacts and these were motivated by a variety of causes. Some of these arose as less physically demanding alternatives to sporting interests e.g. scrabble and chess and some had been taken up as a result of access to classes designed specifically to support people in the community with PD such as Tai Chi. Group activities were organised by local support organisations. In some cases, contact with support organisations led to people taking on new kinds of activities that they considered a personal development while for others the support organisation provided the focus for the type of activity they had envisaged taking up in retirement anyway.

P38 The tai chi's fantastic (..) absolutely fantastic. It doesn't hurt you see. It's all sort of flowing (...) and and you know (.) we walk backwards and things like that which is very difficult with people with it's all Parkinson people (.) and we have a laugh.

P39 We're going to a show next week at <name of locality> and <um> (6...) they've already had one show. Unfortunately we missed it because we was on holiday but <um> (^..) they went to <um> (....) they had <um> day out at the park and a boat ride and they went on to (^..) high tea (.) so (^...) yeah

P12 I wouldn't never have joined a committee or anything if I hadn't had Parkinson's

P44 both locally and nationally (^...) brain banks (..) research networks so yes there's been quite a change (.) a lot of what I do now in retirement (..) is now focused on Parkinson's whereas it might have been something else

Having PD does not necessarily alter people's desire to be active, to contribute to their community. It may even stimulate this. Where participants were used to being active at work, having responsibility, but also having other interests, the onset of PD did not automatically bring an end to the fuller social self or sense of social obligations.

P54 I've gained a couple of friends older friends (er) in their eighties two ladies who I take shopping....I feel as though I can give something back to them really.

However, as well as the opportunities offered by support organisations social contact and activity was also stimulated in more unexpected ways. For example, P37 had to give up work before reaching retirement age and finding he had a lot of time available he enrolled in local adult education classes and trained towards a qualification in computer use. When P55 was no longer able to walk to the local shops he bought a mobility scooter. As well as gaining independence in mobility he found, unexpectedly, that the scooter itself became a prompt for conversation when he was out on it, in the way that walking with a dog encourages people to open conversations which they otherwise might not.

P55 so I'm out and about meeting people which it's funny because I'm in a in a scooter like that and people talk to you 'Hello. You alright?' Whereas if you walk by 'em they wouldn't even acknowledge you you know what I mean? You know why don't they talk to me but they do now. People I've never seen before.

Not all changes to activity would be construed as positive from a social point of view. For some participants their accounts articulated a more solitary existence where more time was spent in activities that did not require social contact.

P64 (..) I read a lot (1.0) I (1...) watch my kindle now (laughs) (1...) and (er) (...) things like that

P60 well I potter about and I do read quite a lot

In summary, some participants described acquisition of activities and contacts since the onset of PD, sometimes adapting to the physical challenges and sometimes taking advantage of the social networks that exist within the PD support community. For some participants this actually offered opportunities for personal development or to maintain their identity as, for example, 'active in retirement'.

7.2.3 Sub-theme (c) Continuity

Many comment that their social life hasn't changed since diagnosis (although a majority indicated that they would like to be doing more during quantitative data collection).

P12 I don't think it has really (..) I can't I can't just think of any at the moment

P44 (...) but having got it socially (.) it it's had no real negative impact at all

Nevertheless, there are various qualifications to this which reveal a more complex picture of change and stasis. In some cases the participants' pattern of socialising was already less vulnerable to impact. For example, evening social

events are more likely to be affected by the medication cycle and so a social life that was previously centred on daytime activities required fewer adaptations. Preferring time alone is also a buffer against restrictions on social contact. There is also evidence of a degree of acceptance that continuation of some activities means alterations may be necessary, that PD imposes limits. This can also mean that activities are maintained but the role the participant plays has been altered.

P45 well <um> (coughs) (1...) no I don't know that it has necessarily. We don't we never did go out in the evenings and things like that

P38 yes but (..) I mean (.) I don't have a mass <um> a big social life I mean I quite like my own company

P14 Well really (^...) I'd like to have a go at it and see okay if in my opinion (^.) that I can't do it (.) then great we'll think of an alternative (^...) but I want to try and carry on doing (..) what I did before I was diagnosed I think we do most other things with <um> (.) with <um> within the <um> limits or constraints of Parkinson's

That's why (^.) I try and do things (.) that I were doing before
P63: no I just tend to hold back a bit more than I used to but that's all

There are particular activities which have been maintained and are mentioned. Supporting a football team, watching a cricket team, going to the pub, restaurants, having people round for dinner, ten pin bowling, quizzes, holidays (specific mention of scooter) voluntary work, accompanying partner on hobby-related visits, girls night out, shops concerts. Participants accounted for this with reference to the preservation of abilities which PD has not yet compromised or where barriers to activity had been overcome.

P41 It has yes (..) but I still get a beer in so I'm okay (laughs) I've still got a sense of humour I think (laughs)

P52 My my mobility is still good enough to allow me to do the things I was doing two or three years ago

P54 Holidays we still go to Lanzarote I take my mobility scooter with me on the plane

Family was often a focus of social activity and participants within the sample spent significant amounts of time socialising with them. Whilst time spent with family was often leisure it was also common that participants' time was taken up in caring roles, for example looking after grand-children but also fitting in with the needs of other family members.

P5 We didn't belong to societies and groups particularly. We did when we were younger but not as we got older no no. We more we just enjoy each other's company and family company you know

P60 (er) quite honestly and grandchildren take quite a lot of our time now and socially I've spent a lot of time helping my <son's name>

P64 I've got the family nearby (..) grandchildren (..) take up some time (2..) (er) family comes first I suppose really

P53 you have to bear in mind that I'm a married man and (er) that (er) I have to or I choose to (erm) fit in with

Some participants also took on caring responsibilities and therefore people with PD should not be construed only as recipients of care. Whilst these roles provided social contacts and in some cases contributed to social life, the reasons for being carers varied and included acting as a volunteer for a charity, supporting others in their social network as well as family. Attitudes to these responsibilities also varied.

P61 (.) well I already sit with one lady who's got (1.) (er) round the corner for <charity> (.)

P51 'cos my mother's ninety four this year (...) and of course I have to sort of semi look after her (...) she's a bit of a pain (laughs) and she doesn't understand (...) what I've got you know

P58 and the social life (..) it's nice to have somewhere to go (.) and there were I was taking my ex-business partner (.) lost his wife about six months ago (.) and he's on his own (.) and he came along

In summary, although some participants claimed that social life had not changed this was not always straightforward. The effects of the medication cycle were described as imposing some limits both on when activities could be engaged in and in how participants participated. Family was described as important within social networks and was a feature of continuity but this entailed responsibilities as well as dependencies for some participants.

7.3 Theme 2 Speech changes associated with PD

Descriptions of changes to speech were very common to this group of speakers, as would be expected, and the range of different motor speech changes they reported corresponded to those that would be anticipated in a group of people with PD including changes to volume, voice production, pitch, articulation and fluency.

A very common feature of change described was difficulties achieving normal volume.

P40 Well I it (...) it's very quiet (1.) you know or it goes very (.) very quiet

P46 Oh yes (^...) my voice is a lot quieter. I'm (^...) have to concentrate to speak out loud (....) otherwise people can't hear me (^1..)

P9 From normal level (^) to going back to nothing and having to take a deep breath and (.) sort of start again

Many participants were not only aware that volume was affected but also that they themselves were not able to recognise the difficulties with volume during speaking. This is a common feature of PD where impairments in sensory calibration result in impaired perception of the scale of movements that are made (Ramig et al, 2001) This problem of calibration means that people with PD perceive their movements to be normal when in fact they are smaller. This affects speech resulting in lower than normal volume which speakers do not self-correct without specialist therapy even where they have some understanding of the problem at a theoretical level.

P16 I said earlier the speech thing you know. I think I'm speaking loud enough (.) and people can't hear you

P44 <um> I'm I'm told it's much quieter (..) though I'm personally not particularly conscious of it (^...)

P41 I mean I /d/ don't (...) I hear my speech clearly to me but other people (.) sometimes question what I'm actually saying

P59 (.) I suppose it probably has (...) 'cos you hear differently to how other people are hearing you (1.)

The motor disturbance in PD results in difficulties initiating movements which were perceived by speakers as a speech dysfluency (stutter/stammer)

P17 Stops and starts that sort of thing you know

P15 or I'll sort of stammer over the first few (....) well over the first syllable

P58 yes (er) (...) I work on that (.) it is (.) hesitation (.) is the biggest trouble (.)

P63 I feel as though (.) I stutter to get my words (..) out more (..) instead of being (.) /fl/ flowing they're not (.) I know they're not these days (1.)

A feature of PD speech is articulatory undershoot, where the target position of the articulators is not fully reached and the resulting speech sounds are inaccurate. Some participants described impairments in articulatory precision which was typically described as 'slurring'.

P18 but <um> (..) this came on gradually and I was (.) speech was slurred

P45 yes yes I I've always think I've got a bit of a slurred speech. It may not be but it seems to me it is. Almost as if I'd had a stroke or something

Many participants described changes affecting laryngeal function especially voice quality and pitch. The motor disturbance in PD can affect the smooth vibration of the vocal folds due to the rigidity in the underlying muscle. This results in hoarseness during phonation. The control of pitch is also dependent on smooth operation of muscles of the larynx and a common feature of PD speech (and dysarthric speech in general) is limitation in the range of pitch, resulting in a monotonous sounding voice (Duffy, 2005)

P8 as I've been told I seem to be on one tone (.) I've got no tone in my voice (.) definition (.)

P15 t was more difficult to (...) put emphasis (.) on (^^...) parts of the story (.) that needed /f/ (^^1.) you know be (.) sort of sound exciting or scary or whatever

P17 some I think my speech is sometimes a bit boring (.) one tone sort of thing (.)

It was evident from their accounts that speech production was not always consistent. Whether a participant was taking medication was important but also the type and timing of medication. Speech production in PD may be affected by medication and speech quality may vary according to the medication cycle (Sanabria et al., 2001). Medication does not always lead to positive variation (D'Alatri et al., 2008; M De-Letter et al., 2006) and so some degree of deterioration in speech may need to be accommodated as part of the overall treatment.

P38 Well before levadopa it was a /r/r/ tremendous strain to speak for any length of time

P40 but I I think it <um> at the minute it's not too bad <um> things have they have improved (...) since I've had this treatment with the pump

P52 I now have a period about say one or two hours after taking (..) my drugs and I take them three times a day (1.) when the physical (1..) (erm) (1.) result of taking the drugs (1..) is jerking legs (er) affect on my speech slightly (..) so I I'm getting more of a hassle from (1.) the side effect of the drugs (1.) than I used to get from Parkinson's alone

Another aspect of PD is increased levels of tiredness which impact motor functions and lead to variation in performance across the day. For some speakers it was evident that this impacted their communication most later in the day.

P64 and then sometimes in the day it's alright (2.0) first thing in the morning's best time for me (..)

P9 It's about average today (.) I think as the day goes on the more I talk it probably gets a bit worse

P6 1 well I don't think I speak as clearly as I do in the mornings (1.) and I think it's 'cos I get tired

During the day, participants felt that situational factors could also influence speech production. For example, in their accounts participants talked about how stress arose during speaking and associated the degree of stress with both positive and negative effects.

P44 (^2...) I'm also aware that (1.) if there's an element of stress or apprehension (1...) that my speech deteriorates

P56 it depends on the company you're in (.) sometimes if you're (.) more relaxed (..) and you're sitting down and watching the telly and sitting round and that that's OK (.) you are relaxed and it seems to me (..) coming to your throat it relaxes your throat (.)

Situational stress may arise from the type of speaking task that is involved. Where the listener cannot see the speaker's face and therefore does not have the benefit of visual cues as to the speaker's meaning this places greater emphasis on the quality of speech (Garcia & Dagenais, 1998). Consequently, using the telephone may lead to greater communication difficulty for dysarthric speakers and this was reported by some participants.

In summary, participants described many features of change to their speech consistent with patterns that would be expected in PD including impairments to volume, articulation and laryngeal function. They also reported inconsistency in their speech performance and variation which they attributed to situational factors.

7.4 Theme 3 accounts of how PD impacts social lives

Participants talked about the changes to their social lives that had occurred since diagnosis and the researcher explored with them the causes of the changes. It was clear that deterioration of speech played a role in the way that social activity and participation changed over time but it was also evident that other factors such as motor and non-motor impairments and the behaviour of others were significant factors too.

7.4.1 Sub-theme (a) Speech

Int: what do you think caused the change in social activities?
P6: it's <um> mainly speech and communication (..) in the (4 syll) (1..) I /k/ can't make myself understood very easily any more

Most participants gave accounts of ways in which changes to communicative ability impacted on their lives in some way. The ways in which speech changes impacted social lives were complex. Speech change caused some loss of intelligibility and this affected how easily speakers could, for example, contribute to conversations, reducing the conversational flow. In addition, speakers self-limited their social contributions to some extent and were influenced by the way that others behaved toward them.

Many participants described how changes to their speech had a direct impact on their social functioning either because their speech was insufficient to support a particular activity or because normal interactional exchanges were no

longer possible. Particular speaking situations may place too much demand on speech production and this may combine with other physical constraints such as increasing fatigue as the day progresses. Participants discovered that they were no longer able to meet the particular demands of speaking tasks that they had previously performed. This affected both personal and professional social interactions. For example, P15 had previously been a nursery nurse and was used to reading stories to young children. As her symptoms of PD extended into her speech she was no longer able to carry out this task.

P11 When I talk on the telephone (..) specially at night time my voice goes
P15 and it was more difficult to (...) put emphasis (.) on (^^...) parts of the story (.) that needed /f/ (^^1.) you know be (.) sort of sound exciting or scary or whatever (^..)

P56 was retired but in a previous role had been called upon to be interviewed on radio, a task he now felt was beyond his speaking capability

P56 so he he was asking me questions about <organisation> and what we did and how it would help young people (.) and (er) that's the sort of thing I had to do so I did get used to it but I couldn't possibly do it

Speakers were aware of the limitations that their dysarthria might impose in the future too and were coming to terms with the seriousness of this.

P40 (^...) I thoroughly hope I can carry on as much as I can (....) I don't particularly want to give up work but I might have to

Outside the professional sphere participants were conscious of the ways that their speech restricted the kind of speaking activities available to them. This

included obstacles to having conversations and to joining conversations.

P64 yes well that's a nuisance because I don't like socialising with people I don't know 'cos I can't (1.) talk to them properly (..)

P36 Well <um> I (..) well I don't socialise as much anyway (.) if we go out I feel a little bit <um> (1.) inadequate shall we say because I can't join in conversations (..)

P8 Yes (..) I don't get involved so much (..) and also (.) my son (.) lots of people say to me (.) "You've not got nothing to say." (..) and I don't say anything because I find it difficult to say anything and also to express myself

Often, problems achieving normal volume in social situations underlay the difficulty in engaging fully with the activity. Even where the speaker is aware of the difficulty and had some capacity to increase the volume this was not always successful and this resulted in a sense of social isolation. Underlying this was a sense that it was not entirely possible to counter the effects of PD simply as a result of one's own choice or desire.

P15 and if there's a lot of people talking (..) and we are trying to (^..) say something (^.) I can't get heard above (...) yeah there's (.) I used to be able to

P56 I held on to it and one of them had difficulty hearing me but I tried to increase the volume (..) but I did make an effort but socially it does cut you out.

A consequence of dysarthria is loss of intelligibility and many participants described how difficulty in making themselves understood affected the flow of conversation. Although they were able to get a message across this required some repetition of what they were saying to make themselves understood. This

can be construed negatively by the speaker and such points in the conversation could become a source of embarrassment even though, or perhaps because, compensatory devices were deployed.

P63 and (er) (1.) I have to stop and (..) get my breath and (.) talk again (..) so (.) it's always breaking off the (.) conversation

P40 and it you know you try and (1.) generally I say something to (^...) to <name of partner> he'll say (....) "What did you say?" So I'll have to say it again (..)

P6 You know what I mean. I know people get annoyed with me if they have to keep asking <um> say pardon yeah. I appreciate what they mean but <um> makes me very embarrassed.

The above are examples of how difficulties producing normal levels of volume and other impairments of speech associated with PD placed limits on what individuals were able to achieve in terms of activities which depended on speech. These might be termed direct limitations on social functioning related to dysarthria. The data revealed that there are also what might be termed indirect factors related to dysarthria which act in tandem with direct factors to limit social functioning. These indirect factors are self-limiting behaviours and changes in the behaviour of interlocutors.

The following are examples of where the participant described how their social behaviour had changed in terms of their approach to social situations. For example, they had become less outgoing in social situations. There was also in indication that this was identified as a change to their self-image. This shows that participants don't simply view speech simply as a mechanistic way of accessing social situations but something which is more bound up with their personality through the ways in which they interact with others. Alterations to

speech had an impact on the way that they construed themselves, e.g. as 'bubbly' or willing to put themselves forward in company.

P38 yes possibly (..) I should think probably in a group you would become quieter

Int: mm

P38: not so bubbly (.) I mean I always used to be bubbly and show off (laughs) but but <um> now that's changed a bit

P54 (erm) tendency then sometimes is for me to go quiet (.) it's against my nature to be like that I like to be involved and have an opinion but sometimes you duck out of it because it's easier to go that way you know

P63 yes, I think I stay back a bit more than I used to (..) instead of (..) going in (..) and saying (.) it's me (1.) I don't do that no more

P64 (..) feel as if I'm (1..) you know you shut up and don't say anything (1.)

Once again the accounts expressed the participants management of their identity making a distinction between the socially engaged former self and the present.

In dealing with their speech impairments these participants found that they were having to confront situations where new choices about how to conduct their interactions were imposed on them by their speech impairments. They expressed a sense that there was a norm of unimpaired or 'natural' speech and also a norm of interactional behaviour which required that they maintain an active role in a conversation. In the situations they now experienced there were additional demands on their ability to produce well-formed speech which at certain points became too burdensome. The effort of maintaining speech quality was weighed against the benefit of social communication.

P55 ‘cos I (er) try to talk as natural as I can and (er) like well I suppose anybody does really (er) but there’s times when (er) (.) (erm) I find that I can’t correct it (.) so then I I try to finish the conversation (.)

Int: You mean. Is that something you choose to do (.) not to talk?

P40: Yes: (1..) which is not the right not the right thing to do really but I think oh I think yeah I just think “Oh is it worth it?”

It was evident that participants were sensitive to a range of influences at play. Sometimes willingness to engage was governed by situational factors such as who the interlocutor was and where communication was taking place. Speaking with strangers, in groups and in public were situations that were more likely to cause speakers to withdraw.

P58 On a one to one basis I’m usually (.) a bit hesitant with strangers (.) not so bad with people I know well

P17 (.) just it’s the group situation I would say for me

P43 <um> I’m conscious of it if I have to speak in public (..) and it seems to have undermined my confidence to do so

These examples suggest that some speakers with dysarthria may have a sense that there is now a risk to social situations which wasn’t present before and which is likely to have an adverse impact on social activity. This can be seen in accounts of specific occasions when a social opportunity or speaking task was refused.

P12 For instance <um> I went to a grammar school that had closed down and <um> I’d had nothing to do with it for a long time then they decided they would have a get together meeting for old pupils
Int: Right
P12: (...) and I wouldn’t go to it. I would have gone if I hadn’t had Parkinson’s

P51 (erm) (..) say at the group I'm asked to thank somebody, if I can get out of it I will do (..) because I'm not happy about (coughs) the way I sound (1.) (erm)

P6 I tend to avoid yeah.
Int: And does it mean you avoid going to places when you might have to speak?
P6 Yes. Why risk either way?

Above are examples of how speakers with dysarthria in PD reported how they responded in different ways to social situations in which their speech differences caused awkwardness. In the following examples we see accounts of how others, the participants' interlocutors, behaved towards the participants in speaking situations. Some accounts described how others can be unaffected by the changes to participants' speech and these reinforce the view that slow change is something to which people can adapt whether in personal or professional relationships. Nevertheless, there is a suspicion - expressed here by P17 - that people may not always be sincere, and this indicates that for the speaker it is difficult to accept that the change in her does not also change the interlocutor in some way. Similarly, there is no behavioural evidence reported that people are treating P43 differently but his understanding of the situation appears to be that what is noticeable to him must also be noticeable to them.

P15 I mean I've had I've had Parkinson's ten years now (^..) so they're not terribly surprised when I (...) start (..) talking (.) differently

P16 I mean the clients that I speak to (..) it's just not an issue to them

P17 other people say "You're doing fine". Whether they're being nice to you (.) whatever you know but <um>

P43 well not overtly (...) <um> (...) the people I I mix with socially or with relatives and <um> (..) and <um> family (...) are really (....) don't seem to notice it at all but <um> I think (..) new acquaintances might wonder why I just hesitate in speech a bit but nobody's passed any particular remarks about it and whenever I've (^...) said "excuse me I (.) got a slight speech impediment" people have said "Well we haven't noticed it" but that may just be being polite (....)

Some participants construe other people's reactions negatively

P17 you're always going to get like we said public situations(.) they they probably think you're being a bit thick or a bit slow or you're a bit old you know

P40 I'm trying to (.) no (...) but like people <um> sometimes I think people think I'm drunk (...) (laughs).

There is general feeling that those who are closer to the speaker are less likely to behave differently towards them. Where differences were noted they tended to be attributed to people outside the groups who might be expected to share knowledge of their experience; younger people, strangers and acquaintances rather than family and friends. These are the people who are expected to find greater difficulty understanding the speaker.

P54 yeh I think older people (.) well you've seen more of life so you understand people being slower anyway whereas young people sometimes wait for you to get to the end of a sentence or can't wait you know.

P41 (...) maybe one or two people who know me (^1...) not as <um> a social friend but (.) for business (..) don't talk to me as much

Int: Right

P41: Purely because (.) they can't understand me or they you know (..) they're embarrassed more than I am

Int: Everyday sorts of things like going into shops. Do you do that or do
P6: I do that but very reluctantly (..) I mean most people are alright (...) Every shopkeeper knows me so when I talk to them they respect me but it would be embarrassing in the (1syll unintell. town?). At least if it's me I'm sure they would be going "Look here" (....) ignorance

In summary, speech impairment was described as impacting social lives adversely by making the work of conversation and interaction harder. This happened in different ways. For example, participants reported that making themselves heard and understood was more difficult and that their willingness to engage in talk was affected as a result of a sense that social interaction carried with it new risks. Participants also reported that the responses of others to their speech impairment adversely affected interactions.

7.4.2 Sub-theme (b) Impact of Motor Impairments

Most participants described motor impairments associated with PD including the classic triad of tremor, rigidity and bradykinesia affecting different parts of their bodies but also dyskinesia, increased levels of fatigue and discomfort which are common symptoms in the disease. For example,

P5 but (um) (..) from then on I used to get this trembling in my legs not in my hands in my legs and (.) went for diagnosis (.)
P40 Yes because apart from my legs freezing it affects my hands. My hands you see
P52 the slight jerkiness I get (..) or the jerkiness (1.0) dyskinesia after taking the drugs (1..) doesn't seem to (1.0) affect my driving particularly at all (2...)
P8 but I found it difficult (..) I was always tired for one thing and (....) you get up in the morning and it takes you half a day to get the stiffness out of you and get moving
P14 I get I find I get a bit tired quicker

P13 and I feel when I'm sat down I have to keep being stood up by something and sat down all the time

The prevalence of motor symptoms in the participants is important to the research questions because speakers commonly spoke of the ways in which their motor impairments impacted their social lives. Control of both upper and lower limbs was affected for many participants and this affected motor actions that are fundamental to engaging socially. For example, walking was limited by symptoms of PD for many participants and this had both a direct and indirect impact on social behaviour. While participants may remain willing to go out the experience was affected by their knowledge of potential problems.

P15 with the Parkinson's (^..) I find I can't walk (..) so that makes me feel (.) nervous and (^.) if I start feeling (.) the slightest bit (^...) funny in my legs and feet I've (^....) I want to go (.) home you know. Know I'm gonna be (^.) safe at home before I sort of (^..) can't walk (...) yeah (^erm^) We still go out as much as we used to.

P15 expressed anxieties about her ability to walk which both directly impacts her activity but also colours her feelings about being out, away from home. Home is a 'safe' place, a refuge from the difficulties that arise from physical impairments affecting her mobility and a refuge from the threat that the symptoms will worsen until she cannot walk. However, she also asserted that the amount that she goes out has been maintained. Nevertheless it is evident that how she feels about being out and how long she stays out have changed. The anxiety shown by P15 is understandable as the consequences of difficulty walking can be serious. Another account showed that independent social

activity was becoming harder to sustain as symptoms worsened. Again, in this account and others can be seen the sense that being out in the world and carrying on normal activities now posed a risk that was not formerly there.

P40 because (^...) because I've got much worse (..) in in the last year (..) and I (...) I usu I fall a lot (^...) so therefore I won't go /gə/ I don't feel (^.) happy about going out on my own

P40 And I can't walk (...) strangers have had to (....) bring me home

P18 (*talking about attending sporting events*) If I got something at the side of me I can grab hold of (..) it's great

Int: but if you haven't got that sense of security

P18: I'd be worried about it

Activities Lost

The limitations imposed by impairments in mobility can have a direct impact on the extent of social involvement.

P13 If I can't (.) if I'm really bad (...) that evening I just (..) think of saying "Sorry I can't come" (..) and in the day as well (.) People understand.

Int: So on some occasions you can't go

P13: No

Specific activities that have been given up or reduced/altered because of motor impairments include types of dances, golf, playing in a football team, dining with friends, writing, shopping, swimming, walking, bowling, travelling, attending football matches, going to the theatre, cycling, gardening and DIY. Sports are frequently mentioned and sometimes this has meant that an activity has been

given up entirely. With it are also lost the social occasions and contacts that often come along with sports, especially team sports.

In some cases, frequency of activity may have been reduced but the activity not extinguished altogether. For example, P14 described how problems with balance meant that he could no longer carry out certain dance steps because his impaired balance put him at risk of falling and initially this had led to a break in taking part in a very long-established social activity

P14 it's got to a point where (^...) there are certain dances I can't do because I if it involves something like (...) <um> a turn (.) I lose my balance

However, he and his wife had developed techniques for coping with his movement difficulties during other dances and adapted to the changed circumstances by being more selective about the dances they opted in to. This meant that they could still attend and be involved in the social circle and events that they had previously but with the loss of some freedom to be spontaneous.

P14 So the wife has to grab on like (.) make sure I don't go (..) <um> (...) <um> obviously we we didn't go dancing for about (.) /l/ last (.) /w/ she's been in the dance group but she's not been (.) you know it's been okay for her (..) but I hadn't been able to do any dancing (^...) <um> because I'm frightened of you know this falling over problem (..) but we went to a dance yesterday the second one we've been to (^...) <um> in the last (.) perhaps four or five months (^...) didn't involve this problem of spinning (....) and <um> yeah we had a great afternoon <um> it's just a case of pick and choose whereas before (^.) we could just go on and do it (.)

It was not just the physical impairments but their particular consequences and the anticipated consequences that some participants found socially limiting. In this sense participants differed from 'well' people in social situations who might

experience occasional physical or speech missteps but who do not expect these to be recurring features which need to be managed. These examples indicate that speech may be only one aspect among several which speakers have to consider when they spend time with others. P8 demonstrates the compounding effect on socialising of different types of impairment; speech, non-motor and motor.

P4 Well this leg freezing is very frustrating (..) and you know if you are going to the bathroom and you're dying to spend a penny or something (..) I (..) you (..) you're stuck you know. It's horrid.

P43 <um> I'm a lot more cautious about dining out with friends but <um> I've got no inhibitions about talking about the (..) problems that I have and the <um> (..) the people I mix with have generally (..) not (..) been phased by it

Int: You say you're more cautious about dining out?

P43: /w/ well it's difficult at times to <um> swallow (..) and everything I do is very slow (..) including eating and <um> at some stage it may become socially difficult if (.) I'm so far behind everybody else (.) when we when we're eating

P8 before I was a keen cyclist so I biked from <name of city> to <name of city> for the <name of charity> <um> had a mountain bike (.) I was a lot thinner obviously <um> and <um> my social life was different (.) I walked a heck of a lot more. I could do a lot more and I was full of energy (.)

P8 and <um> (.) that was another thing I had trouble with (.) talking to people and then I start dribbling (.) always out (..) the same side as I got Parkinson's (...) yeah (1...) yeah (...) but I've learnt to control it (1...) yeah that was another thing I found (.) but my social life yeah (.) <um> you know my activities decreased slight I love gardening DIY (...) but (..) you can't (.) turn it. I can't put a screw in anything. It's just (..) virtually impossible (....) so it altered lots of things (...)

An aspect referred to by participants which relates to motor impairment was medication. They talked about effects of medication and how the medication cycle impacted their social lives. Taking medication and working around the

demands of the cycle means lots of planning. In fact planning is a new feature of daily life. Medication is a source of worry when out of the home because of unpredictability which can be profoundly destabilising. As Green et al's (2010) account of living with PD puts it, 'The unpredictability is Parkinson's keynote. It is chaos.' (p 208).

P51 but it varies (1.) (erm) now the thing is if you if you go out (...)(erm)(...) and you're not quite sure when you're going to switch off (..) you see (...) eventually (.) medication just doesn't (.) work so well (..) and you find that the times in between are getting less and less (1.) (erm) (..) so (..) and I think when you you're worrying about (.) are you going to go off (..) you probably will do because you're (.) not relaxed you see.(1.0) so (.) it's always a bit of a sort of bit of a worry (1.)

P38 There's no-one to sort of back you up (..) and <um> (.) it it can be tricky but (...) the thing to do is get organised and do everything before you go off

The cycle has an impact on the activities of participants in various ways. In some cases, conscious that once the participant has entered an off period in the evening many routine actions will become much harder to do successfully, the order of daily activities has to be managed more carefully. For example, cleaning one's teeth is not left until bedtime but brought forward to early evening. Being in an 'on' or 'off' phase influences decisions about how long to spend with other people. Underlying this is the need to plan the day carefully, working around the periods of better and poorer mobility and ensuring that medication is available. Managing this is an important factor in reducing spontaneity.

P38 (.) I even clean my teeth because (^..) even that's difficult when you're off

P59 probably yes because if I'm feeling to to go off I prefer to take myself out of the company (2.0)

P53 We have to think about (er) what I'm going to do (.) how long it's going to take (..) what I need to take with me as far as medication's concerned (erm) can I undertake this because of the Parkinson's (.)

P60 I'm generally I'm often up and ready an hour before we go but (erm)

In summary, motor aspects of PD were present as would be anticipated and participants attributed to problems of mobility some negative impact on accessing social situations, for example limitations on walking. The impact of the medication cycle on loss of spontaneity also played a part in participants' stories. An important aspect of these accounts was negative feelings towards being away from a time or place of safety.

7.4.3 Sub-theme (c) Role of Others

The symptoms of PD are not only apparent to the person who has PD but also to those they come into contact with. A prevalent sub-theme in relation to PD was the ways in which the behaviour of others impacted their lives. Other people responded and coped with the challenges presented by PD in various ways both positive and negative and it was evident that this was important as a factor in the way that participants understood their social interactions. This data is relevant to the research questions because it bears on how people prefer to engage with people in the network and what sort of behaviours put pressure on those contacts and also what sort of behaviours encountered are likely to encourage social contact or activity.

Many participants were aware of differences in the way that people behaved towards them. Some participants reported sensitivity to being looked at or feeling judged by people with whom they came into contact, particularly strangers. There was a belief that this is understandable human behaviour, especially among children whose social skills are not fully developed and who display a naive curiosity, rather than any attempt to criticise or judge in return. Nevertheless, being the subject of unusual scrutiny was for these participants uncomfortable.

P12 Children don't like it. I've found that children really don't like to see. They look at you you know (..) little children

P60 (erm) if I do freeze I feel really (..) 'cos some people think you (.) I've had one woman thought I was drunk and (er)

P8 <um> if you went out (..) <um> people would <um>(.) like children. Some children "Why's that man shaking so much?" (.) and that would embarrass me (..)

P37 when you're stuck and you're in a hotel or something (....) people do look at you (.) I mean it's only human nature (..) but I used to feel really (....) <um> conspicuous about that you know people looking at me

Some had clear ideas about the kind of interlocutor behaviour which was desirable and which was not. More acceptable behaviour was that by which others displayed an orientation to the person with PD as not being different, although this did not mean ignoring the fact of the condition. Others could display this orientation by sharing a joke, carrying out habitual or everyday activities together or not treating the participant as a patient. Where the emphasis was on the person, not the condition, this was appreciated.

P37 I've got some lovely friends I meet down there and they (^..) I'm I'm <name of participant> . I've not got Parkinson's. I'm the normal <name of participant> that they know and we just have a laugh and a joke you know go to watch the football or watch the rugby sometimes

P7: But usually they just pass the time of day. And that's all you're wanting to do really you know (.) they just (.) keep chatting away like (.) don't want to keep saying "How are you? Have you got this that and the other".

P17 like most of the people I meet (.) now I've got Parkinson's anyway they tend to (.) they know (..) I'm trying to get a sentence out (.) just let me get which is the best way really

P63 yes 'cos people look and say 'Why is she doing that?' they ought to come just ask and then possibly you know that would be better than just staring

Participants were sensitive to and critical of behaviour which was overly solicitous.

P36 Well we noticed it a bit (..) over the weekend didn't we <name of partner> ? (..) that <um> people will sort of come and (.) to your aid (..) which isn't always (1...) appreciated

P37 But before I always went to work (..) I always managed everything (...) and people didn't <um> didn't (^...) they changed not in the beginning not in the no not (^1..) now I think they probably feel sorry for me (....)

P63 People fuss more. You know 'Are you alright?' I just feel as though they should (.) not do that so much 'cos it makes it more (.) aware of what I've got

In contrast, offers of practical help could be encouraging of social interaction or offer a way past a particular obstacle to a social opportunity. This allowed some participants to maintain activities that would otherwise have been dropped

P36 and so I'm confined to the village (.) unless <name> takes me out

P37 and <um> I mean (.) I didn't go out to anything with sports but people (..) take me out and about all over wherever I want to go you know and (.) people are very good with me

P44 for example if I'm flying my aircraft and I get (..) if the tension builds up to the point where the tremor is causing me problems with the aircraft (^....) one of my flying colleagues will step in and take the (..) control over (...) so there is a (...) a physical (....) assistance

P51 He gives me confidence because if I was out (...) you see (.) he'll say 'Go to that do,<name.> (.) and if you feel (..) just give me a ring and I'll be there in (1.) I've got that back up

P63 No no they come and sit and talk to you 'cos you (..) 'cos mostly you're sat down (..) like at a (..) gathering or a party or something (..) you know people do come and talk to you (.) which is nice

Treating the person with PD as not being different did not mean ignoring the symptoms of the disease or pretending that nothing was wrong. Participants themselves demonstrated an acceptance of these symptoms in these accounts and an ability to confront them in their own language and they valued occasions on which others reciprocated. In this way others demonstrated that they were accepting that the visible motor symptoms were part of the person but didn't signify more, the person they knew being still the same. Sometimes other people were unable to achieve this level acceptance and this evoked strong feelings in the participant.

P52 No (1..) I I'm very lucky I think that my relatives and friends (2..) just accept that (2..) if I'm jerking a bit that's it

P59 and I said 'I didn't realise I was nodding so much' as a (2 syll unintell) she said 'I love I love Noddy' she said (.) it was just the right thing to say (.)

P60 They know who I am and they accept that you know I've got a bit of a dodgy walk

P51 and some people are a little bit frightened you know

I: mm

P51: My neighbour she's lately I mean we get on she's almost like a best friend (...) but she came in once and I said, 'Do you know I'm going to go off a bit now.' I said, 'Just' (..) she 'oh oh well Ok I'll leave you then' and she was off (1.) but and and that worries me (..) when my granddaughter my eldest granddaughter's here on her own she helping me do something (...) and I was going and I could see she felt that little bit of (.) uncertainty and that I hated (...) as <name> says this he (...) on on one of his videos he says (erm) I feel like a monster (1.0)

In summary, participants interpreted others' behaviour towards them both positively and negatively. They demonstrated a preference for person-centred behaviour which supported or emphasised the continuity of relationships and activities and which placed Parkinson's disease in the background but not necessarily out of sight. Behaviour which foregrounded the condition, whether by unusual scrutiny or by offering unnecessary help was construed negatively.

7.5 Theme 4 Participants' Response to PD

Examination of the transcripts showed that the feelings that were engendered by PD and its impact on their lives formed a theme within the data. There were two main sub-themes within this theme. The first to be explored is that of the emotional impact of PD and its consequences, which is generally negative. The second sub-theme revealed was that of emotional resilience in which participants accounts delineated the emotional resources that they brought to bear in coping with PD.

7.5.1 Sub-theme (a) Emotional Impact

People with PD are at increased risk of depression (Rickards, 2005) and this was described by some participants when speaking about the background to changes in social life. Participants gave accounts of low mood occuring at different times during the course of the disease and these and other negative emotional events which arose as a reaction to the condition were evidently a significant factor. News of the diagnosis could have a profound effect, a life-changing effect and the catastrophic language of their accounts provides evidence that these participants were dealing with major pressures on their mental health which they had to deal with alongside their motor and speech impairments and which at different times may be a higher priority for them. On a day to day basis coping with the disease and with the additional burdens it imposed could lead to fluctuations in mood.

P18 doc <name of doctor> 's very good (1..) <um> (...) he told me that I'd got Parkinson's and I thought (2s) the whole world had crashed (.) <um>

P37 but <um> and <um> and I felt (.) I felt (.) I felt terrible and that sort of thing (..) and <um> (...) <um> that's been my worst thing at all of anything really

P6 Oh it's changed in the last five years. It gets depressing very depressing at times.

P59 (erm) you know the day before because getting ready to go away for a few days is an effort and (erm) you know you begin to get non positive thoughts

P10 don't feel the best way is to be angry about it but (5s)(tearful) I can't get rid of my anger.

Participants spoke about other feelings they experienced and which were affected by PD. In relation to social interaction, loss of confidence in particular was important to some in that this directly impacted willingness to interact socially and professionally.

P11 I can't <um> I don't feel confident like I used to
Int Right you mean in meeting people?
P11: yes

P41 cos of my con my confidence has got lower (2s) which another thing in the business world is quite difficult because I need to be forward with what I'm doing (2..) whereas I let others go forward no (....)

P51 well it's just this not knowing (.) you lose confidence (...) because (1..) you see at one time I could say I'll take a tablet I'm going in to <place name> shopping (..) and what well a couple of hours I'l l be fine (..)

P43 <um> I'm conscious of it if I have to speak in public (..) and it seems to have undermined my confidence to do so

This was sometimes expressed quite subtly, for example in this account by P41, a relatively young man, used to socialising in a pub where conversation moved quickly and contained a lot of humour. His perception of himself as being at the centre of such interactions had changed. He still 'fitted in' but could no longer play such a central role and this movement to the periphery was felt as a loss to him.

P41 Accepting that (...) it's not that I don't fit in but I (1...) I don't stand out in the crowd any more whereas maybe before I was a bit more (^..) outside a couple of beers I get a bit lively do you know?

In these accounts there is a sense of uncertainty about coping with interaction and when this was explored with participants negative emotions were described by some speakers associated with problems they had with speech. This could be expressed as dissatisfaction with their speech. Sometimes awareness of impaired speech affected the whole cast of their approach to social situations, whether they would feel positively at all towards the situation. At other times the focus was particularly on presentation of self in the public or social sphere and the emotions associated with loss of face.

P51 Well I talk slower and I've heard (..) heard it played back you know I think 'oh crikey' (1..)

P16 Yeah (...) it's difficult to be (.) positive when (.) you know people can't hear what you're saying.

P18 as I say it began (1..) to get (2s) embarrassing. It was noticed (cough) slurred speech (.) slurred and (..) what have you

P6 I mean some days I mean it's not too bad (...) but to me I I personally I (.) talking now I sound as if I mumble (1 syll) but it can be very embarrassing

Similar feelings were engendered by participants' awareness of their motor impairments and by uncertainty concerning motor fluctutations. Participants described their perceptions of the evaluations others make of them when they display their symptoms in public and how this made them socially uncomfortable.

P12 Well I've got I've got <um> (....) quite a bad tremor (....) and (..) I know that people immediately look at you then look away you know. Yeah I am (.) I <um> think that's the thing I'm most conscious of

P38 It it sort of tends to (..) there's a problem you know "Will my medication last well into the evening?" or <um> (2s) you know "Will I get some dyskinesia?" which it can be a bit embarrassing

P56 Yes I tend to drop quite a lot yeah well you're not going to go to <restaurant> and then dribble down all the time (..)

P6 Oh yeah and then I can't walk (.) shaking in a wheelchair people looking about think you're stupid you know.

In their accounts of self-consciousness participants indicated a normative approach to social behaviour. Presenting as having Parkinson's disease in public spaces was undesirable to some participants and this presentation related to speech and to non-speech motor symptoms.

In some cases this was linked directly to giving up social activities and this can be seen in the explanation of why P45 and partner gave up bowling.

P45 we found we found we were making a mess of it so we stopped

P45 construes bowling with PD as 'a mess'. In other words, their bowling was no longer meeting what they felt was an acceptable standard to be worth continuing. Again, the consequences of poor performance were different from what would be expected by the unimpaired person. For the person with PD such moments parted them from their earlier life.

Normative views towards physical capability were expressed by others. P12 made adverse comparisons between his present condition and that of his youth when choosing not to attend a school reunion. P60 evaluated walking critically and this was the basis of feeling self-conscious in public spaces.

P12 I wouldn't go because I felt that I (1.) last time I saw all these people I was a fit young teenager

P60 sometimes if you go into I go into a room say the dining hall or something and you're not walking very well I feel conscious of it very conscious but (erm)

In some cases the impact of impairments of mobility on self-presentation was very personal. P38 identified an aspect of her physical limitations that she acknowledged was gendered and might, to some people, appear quite marginal to social activity However, for her it was very important, a life-changing issue, and this was because it was a significant aspect of her social presentation.

P38: yes even walking you know(.) you can't wear high heels and so you're going to a social thing and there's (.) they sound ridiculous probably to a man but (laughs) no but <um> that's the sort of thing that changes your life (....)

Hiding PD

It is evident from these accounts that awareness of physical and communicative presentation engendered embarrassment and self-consciousness in social situations. This self-consciousness is related to accounts in which some participants spoke of wishing to hide their PD which affected social interaction in various ways, just as described by Beth, the focus of a qualitative case investigation (Bramley and Eatough, 2005). An example of this is seen in P51 below in which she spoke of managing her medication in order not to appear Parkinson-like, to mask the cardinal symptom which she referred to as the 'wobbling' to give her time with others when she didn't look as if she had PD.

Other participants spoke more explicitly about how they concealed the condition at different times in social situations by using strategies such as positioning themselves inconspicuously or self-limiting behaviour which might reveal their symptoms, such as speaking. In some cases this meant avoiding entering a social situation altogether which is a cost associated with illness concealment (Macrae, 1999).

P51 I went ten years without levadopa (1.) and that was (..) that was difficult (...) and (.) now I take more because (.) some people look as if they got Parkinson all the time (...) you know the wobbling. I don't want that (.)

P18 'cos if you sit (.) if you go to the back of the /s s/ standing space you can lean against the wall and nobody'll probably know anyway

P42 I probably don't talk as much when I am out (..) perhaps shopping (.) when I know I'm going off <um> because there again that's hiding Parkinson's

P37 when I was first off I thought I'm not going to go 'cos people see

In summary, participants described a range of negative emotional responses to their PD of which loss of confidence in projecting themselves as competent in social situations was significant. Accounts revealed a normative view of physical and communicative presentation to the world and, related to this, some participants described ways in which they took efforts to conceal their PD from others.

7.5.2 Sub-theme (b) Resilience

Although some participants spoke of the negative emotional impact of PD including specifically the involvement of speech impairment in that process, a

majority of participants gave accounts which displayed an orientation towards PD of resilience in various forms and common to these was a sense that people should take an active rather than passive role in response to the disease. Some accounts centred on strong perceptions of self, such as being independent or in control and therefore not being dominated by PD. Others centred on acceptance of their situation and adaptation to their limitations. It is important to note that these two sets of accounts were not exclusive. In fact 11 participants gave accounts both of the negative emotional impact of PD and of aspects of their personal resilience to the condition, which strike a chord with other accounts (Gatt-Rutter, 2012; Bramley and Eatough, 2005). It is therefore evident from these accounts that explanations of any relationships between emotional factors and social behaviour will be complex.

Showing PD

Public presentation or depiction of Parkinson's disease is uncommon (although a creative example of this is the collaboration of Green et al. (2010) which incorporates the experience of PD into artwork). Nevertheless, some participants rejected a concealment approach to their PD symptoms and took instead an approach to public presentation of their symptoms which demonstrated a sense of owning their symptoms and the consequences of them. In these accounts the participants showed that for them PD was not something alien or separate from their sense of self but that it was now part of them and although not something which they celebrated it was at the same time not something to be ashamed of or concealed. So some accounts in this study told a story of PD as in some ways self-actualising, as has been done

elsewhere (Fox, 2003; Issacs, 2007). This influenced participants actions in social situations in general ways, such as taking the initiative, and in particular interactions where others evaluated their Parkinson-related behaviour negatively, e.g. P38 below.

P61 No nothing affects the way I interact with people because I thought long ago I can't help it this is the way I am (1.) so I'm not gonna I'm not embarrassed about it which a lot of people are and I'm not (1.) this is me this is what you get. Whether you like it or not (1.)

Int: Yeah. So you take the initiative
P13: Yeah (..) some people try to hide it away but (...) I've always been the same

P38 I was in <name of store> and having a fairly (..) awful day for some reason (^..) and I did keep dropping things and <um> (laughs) I dropped something at the cash and <um> (.) and then I dropped my card and the woman at the (.) /sə/ ə /next to me (.) she was elderly (.) and she said "Oh golly she's even dropped her card." EVEN dropped her card. So I just went up to her quite politely put my face against hers and said "I have Parkinson's disease. I'm expected to drop things."

P43 <um> I've got no inhibitions about talking about the (..) problems that I have

Independence

The disruption caused by PD to one's sense of self and of being autonomous has been documented elsewhere (Bramley and Eatough, 2005). Being independent and being treated as independent was important in many accounts in this study. Many accounts referred to independence as a trait, an aspect of their former personality. These accounts emphasised continuation rather than contrasting past and present indicating that maintaining independence was

important to their core self. Participants liked to be able to display independence in specific ways. This might refer to specific interactions e.g. coping with money at the checkout, or thinking about life in the longer term, such as being able to remain in the family home. There was a desire to continue to do things independently, even though that meant taking longer to do them, rather than accept help, emphasising the psychological importance of this.

P42 'cos I suppose it's because the type of person I am (^.) I've always been very independent and very (..) I I do things. I cope on my own you see

P37 don't try to mollycoddle me which I don't want (.) no I don't want any mollycoddling

P51 but I'm determined I mean (laughs) I'm not going to leave. I don't want to leave my home

P54 Things that I can do (1.) it frustrates you then when somebody (..) is is difficult you know

I: mm

P54: they try to do it for you (.) when you know you can do it for yourself you know (1.) even if it does take longer

When some participants talked about their attitude to PD this was often couched in a language of resistance in which PD became an enemy which threatened their quality of life, e.g. 'I've got to overcome this', 'I've got to fight', 'I don't want to give in to it'. In these accounts the matter of living with the progressive deterioration of PD is a struggle which can have a positive or a negative outcome and this is not solely determined by the progression of the disease but can also be influenced by the attitude of the person.

P11 Sometimes yeah. But I don't let it (...) <um> I think I've got to (^....) overcome this (..) you know I don't want to give in to it

P52 although I am a bit more anxious about my ability to do speaking (..) I'm damned if it will stop me doing something I believe is worth doing

P61 I said 'Well no I can get the bus. I go everywhere on the bus.' (1.) I said (1.) 'No I'll it's not a problem' (..) Anyway they decided to come to me (..) and because of my attitude (...) she said to me (1.) I think I'm really looking forward to meeting you (1.) and I thought 'Oh that's a nice thing to say' (1..) so my attitude is everything. Well I know I I (1.) I can't just lie down and take it (.) I've got to fight (1.) because I I just don't want a life of sitting in a chair

As can be seen in P61's account above, some participants explicitly recognised the importance of positive attitude as beneficial for individual interactions as well as for maintaining the kind of quality of life they valued. This positivity was also construed as a choice between one type of response and another and that choice was in the control of the speaker.

P18 so <um> (1...) I've had the <um> well (3.) as I say (....) the after a time (....) you <um> (1.) you know all you know you're not going to get any it it's not going to go away

but <um> (..) I think it's all it's all to do with (...) mind over matter isn't it?

P52 You can either make yourself miserable or (.) if not make yourself happy. I think there's an element in every illness (.) and I'm very lucky Parkinson's isn't that bad (..) but I think there's an element in any situation where (..) if you want to be miserable you can make yourself miserable as easy as pie (..) there is an element of you can choose which way it goes

P37 I couldn't go to work and (..) I felt (..) a bit useless for for six or nine months (..) I I've I've changed my attitude and and and it made it better for me.

P51 but (erm) (1...) she she's she'll make a life for herself (.) and that's what you've got to do really

Other accounts were sometimes more fatalistic. Nevertheless, these accounts also demonstrated an attitude of fortitude and participants expressed the view that they had a role to play in actively dealing with the situation as they found it rather than passively accepting things.

P18 Yeah well it's <um> (4s) I get (1...) I look at it like this (..) you've got it (.) that's it you can't do anything about it (.) you grin and bear it (...)

P14 I try to make it that (.) I try to do what I did (^..) before I had this so (^..) just got to wait and see.

P37 Got a lovely wife who helps me and we've been married (...) forty three years so (..) and yeah I mean (.) I've got nothing to worry about really so I should get on (..) that's what they tell me and I should do and I do do now

P59 yes it is because yes if you step back (1..) it's going to be more difficult to step forward you must keep where you are or keep stepping forward (..) because if you step forward it's so (...) psychologically it does you a heck of a lot of good (1.)

Despite this positivity there was evidence that some participants recognised the very great emotional challenges of adapting to their changed and changing situation, that coming to terms with having PD was harder even than dealing with the symptoms. It was not the case that having PD was considered to be a blessing in disguise. Rather, it was, as P51 put it, necessary to 'respect' it as one respects something that is powerful and essentially outside one's control.

P41 It's just that I got to accept a new way of life. Me getting used to it is probably harder than anything

P44 (1.) Oh I yeah I'd rather not have Parkinson's (...)

P51 P: but I respect it (...) and you've got to respect it because (.) you think you're doing fine it's a wonderful feeling I I've had a good patch (.) since

Christmas (.) (erm) (...) (erm) (1...) but you see this morning I', I'm not in control (1.0)

The accounts also showed that people responded emotionally to the challenges of their situation in a variety of other ways that could be considered positive. For some it was helpful to compare their situation with that of others and saw themselves as relatively lucky. For others, it was important to keep PD in perspective, not ignoring the fact that normal ageing brings with it change and challenges that must be faced as well and rejecting the option of self-pity.

P16 there are people a lot worse off than me. Oh (..) you know one of my friends just got prostate cancer and I wouldn't swap places with him for anything

P38 Flat shoes can look quite attractive (.) so think of it like that. And as you get older you change anyway (.) so therefore it's not (^.) you mustn't blame everything on Parkinson's

P42 but it's only because you don't want people to say "Oh you poor old thing" and feel sorry for you.

Int: Right

P42: 'cos I don't feel sorry for myself you see

P38's account is unusual here in that although she acknowledged changes in her life she did not emphasise PD as the cause of changes, unlike accounts reported above, and so reveals the individual diversity in the perspectives of participants. For P38, PD was something to be deliberately managed and controlled rather than something which controlled her. In this respect she fits Anderson's (1999) observation that the idea of a healthy person with PD is non-contradictory.

In summary, alongside the negative emotional responses to PD there were various expressions of emotional coping and suggestions of emotional development. These accounts placed a high value on independence and autonomy and PD was construed as a threat to this. Participants often expressed their views in a language that foregrounded a narrative of stoicism and resistance.

7.6 Hierarchical Links Between Themes and Sub-themes

The themes that have been presented represent the most prevalent and recurrent ideas in the data set and these have thus been treated as units of meaning as expressed by the participants. Although themes are separated in the analysis there are many links between them. The thematic analysis is organised structurally as a hierarchy in which a number of sub-themes relate to superordinate themes and this organisation reveals how groups of thoughts and ideas cohere together within the data set as a whole. There are also links horizontally between sub-themes and between theme, some of which have been described within the thematic analysis (such as the links between mobility and attitude towards displaying PD) and some of which are explored here.

Links between orientation to PD and role of others

One example of a horizontal link between sub-themes is the link between ideas participants expressed about being independent and how others behave towards them. Where participants discussed their desire to be or remain independent this was sometimes related to the benefits of preserved mobility

and disadvantages of deterioration in physical abilities which presented obstacles to independence but it was also discussed by some participants in relation to how others contributed through different types of behaviour. This behaviour can be both positive and negative from the point of view of the participant. For example, when P54 expressed some dissatisfaction with his sister's behaviour this was because he felt treated as lacking independence. On the other hand, some people's behaviour could be socially positive for participants and help them to have greater independence. This can be seen in P51's account of how knowing that a family member is available to support her if necessary increased her confidence to go out on her own.

P54 My sister's twelve years younger than me. She perhaps makes too too much of an allowance. We don't see each other that often although we're not far away (2.0) she sometimes over-allows things you know. Not saying treated like a baby, that's going a bit too far but you know

P51 He gives me confidence because if I was out (...) you see (.) he'll say 'Go to that do,<name.> (.) and if you feel (..) just give me a ring and I'll be there in (1.) I've got that back up

In some accounts, support from others over a period of time has been important in developing a more independent approach to socialising and this demonstrates that some participants valued particularly an appropriate level of help as facilitating the process of gaining independence. This can be seen in P37's account where he expressed appreciation of help but was also adamant that 'mollycoddling' was not appropriate (see above). There is also the

possibility of a reciprocal benefit occurring in which the participant's self-reliance can be rewarded by other people, which can be seen in P38's account below.

P37 Got a lovely wife who helps me and we've been married (...) forty three years so (..) and yeah I mean (.) I've got nothing to worry about really so I should get on (..) that's what they tell me and I should do and I do do now

P38: it's terribly difficult <um> (.) it's just a question of learning to pace yourself (....) and that's how you cope (.) and I am determined to cope (..) and that's another thing if if (.) you know a Parkinson's nurse said to me (.) <um> (.) "Make no mistake. Your attitude (.) has helped you get where you are today" (....)

Links between change to speech and social impact of PD

Participants talked about how their social lives had changed and about what they felt were the causes of those changes. They also described changes that had occurred in their speech and as would be expected there were links between those changes to speech and how participants accounted for changes to conversational exchanges that occurred in social situations. In section 7.4.1 above the impact of speech on social functioning was explored as a sub-theme and the data revealed a range of issues that were important. In this way, the linkage between the two parts of the thematic structure has already been explored but there the focus of the analysis was on the variety of types of impact that was experienced, including how social roles had changed, social withdrawal, change to conversational dynamics and a sense of risk attached to social interaction. The links made here refer to the ways that particular aspects of speech impairment had a detrimental effect on social interaction. For

example, changes to volume were described by some participants and it was evident that the loss of volume in speech was perceived as being at the centre of difficulties that were experienced in interactions and that, in turn, these difficulties impacted how easily participants could fulfil their usual social roles.

P8 um> as I said (.) because we're in a quiet environment here (..) and I can hear you (.) I can talk pretty well (..) but in (.) social <um> areas I find it difficult because I tend to start loud and go soft (...) and (.) lots of times in the car my wife can't hear. My sons on the phone (.) they say "Are you there?" and I'm talking but it's not loud enough (..) They struggle to hear me (....) <um> I I do have problems with that (....) yeah.

P40 and (..) when you do speak people (1...) ignore you so I assume they have not heard what you've said

P41 'Cos people can't hear me in the pub (...) the voice development is (^..) it's gone softer

A range of speech impairments were described by participants, as detailed above and, like volume, these sometimes played a specific detrimental role impacting communication in social situations, either alone or in combination. For example, articulation impairments and loss of fluency underlay particular incidents where participants were unable to maintain output and where communication was disrupted as a consequence.

P55 'cos I (er) try to talk as natural as I can and (er) like well I suppose anybody does really (er) but there's times when (er) (.) (erm) I find that I can't correct it (.) so then I I try to finish the conversation (.)

P43 I I would (.) get halfway through or very nearly through (^..) and then be lost for a word or (.) just hesitate before I could complete the sentence (..) <um> (.)

7.7 Theoretical Explanation

Theoretical constructs were developed alongside the thematic analysis with a process of ongoing refinement as the recurrent ideas emerged. The aim of the theoretical constructs was to provide an underlying explanation for all the themes and sub-themes which was relevant to the research questions and which was prevalent in the data set and which would explain the hierarchical relationships between themes and sub-themes.

Two constructs were developed to account for the data. Participants discussed social changes in terms of

- direct (or symptom-related) influences
- indirect (or personal and social) influences

These two constructs can be incorporated into a single model. There was evidence within the data that the symptoms of PD had an effect on social lives which was seen in the way that these symptoms placed restrictions on specific actions which were necessary to enter or satisfactorily complete social interactions. This was observed in relation to speech, in relation to motor impairments affecting limb mobility and also in relation to non-motor symptoms

P36 if we go out I feel a little bit <um> (1.) inadequate shall we say because I can't join in conversations

P63 and (er) (1.) I have to stop and (..) get my breath and (.) talk again (..) so (.) it's always breaking off the (.) conversation

P12 Well I've got I've got <um> (....) quite a bad tremor (....) and (..) I know that people immediately look at you then look away you know. Yeah I am (.) I <um> think that's the thing I'm most conscious of

P45 and I can't really talk when it goes dry (^1.) without some lubricant to (^..) release it as it were you know

P54 you're still processing what somebody else has said and the conversation's moved on two steps if you like you know

P41 My reactions to humour can be different. I can explain (1.) I don't see the joke immediately (.) as well as I was sharper before (.) I /d/ don't pick up on things

Although speech impairment was frequently described as an obstacle to achieving a satisfactory social life, mobility played a very significant part as a barrier to achieving this too. It was evident that the impact of speech impairments on social activity was part of a complex inter-related set of factors and that where speakers were managing impairments of speech, mobility and non-motor functions, different aspects of their PD may have been more salient in decisions at particular times depending on a range of other factors such as the demands of the social situation, severity and fluctuations in their symptoms. Both speech and motor impairments contributed in different ways to changes in how social lives were conducted in the same individuals. For example, P15 reported that she had not reduced the amount she went out with her partner and friends but that awareness of the possibility of onset of dystonia made her nervous about staying out and this tended to curtail the amount of time spent out. Additionally, her problems with maintaining a normal conversational level of volume in speech presented difficulties in taking a full part in conversations, within her regular church group.

P15 I'm more (^2s) prone to want to go home early if we go out (^....) because I get dystonic

P15 and if there's a lot of people talking (..) and we are trying to (^..) say something (^.) I can't get heard above (...) yeah there's (.) I used to be able to

It can be seen from this account that both speech and motor impairments impacted on social functioning but each was a more salient factor depending on whether the activity was likely to be longer or shorter and how large the gathering was.

A second construct was identified which included the indirect influences on social interaction and activity. This construct concerned both the personal resources that participants brought to their situation of living with PD and also the ways in which others acted towards them when their PD was made known. Whereas the direct influences of PD symptoms on social change were almost entirely negative in the accounts of the participants, the indirect influences had both negative and positive influences on how social lives were conducted. For example, P37 above in his account described how his feelings of depression which followed from his diagnosis had contributed to increase social isolation but over time he had developed more positive feelings towards his situation and his social life had become more satisfactory. P51's account is an example of how the supportive behaviour of others enabled her to be more confident about going out but also how the reactions of others to signs of her motor impairments reduced some of her opportunities for social contact.

The role of the indirect influences is therefore key in how people with PD maintain or develop social activity and contact but is closely linked to the direct influences. Participants are aware of their symptoms and how they present to others, they react emotionally to this situation both positively and negatively and others with whom they come into contact also react and behave both positively and negatively in terms of encouragement to continue or develop social interactions. How participants construed themselves, for example as being independent or refusing to give in, was very important in participants' accounts relating to willingness to maintain or enhance their social life.

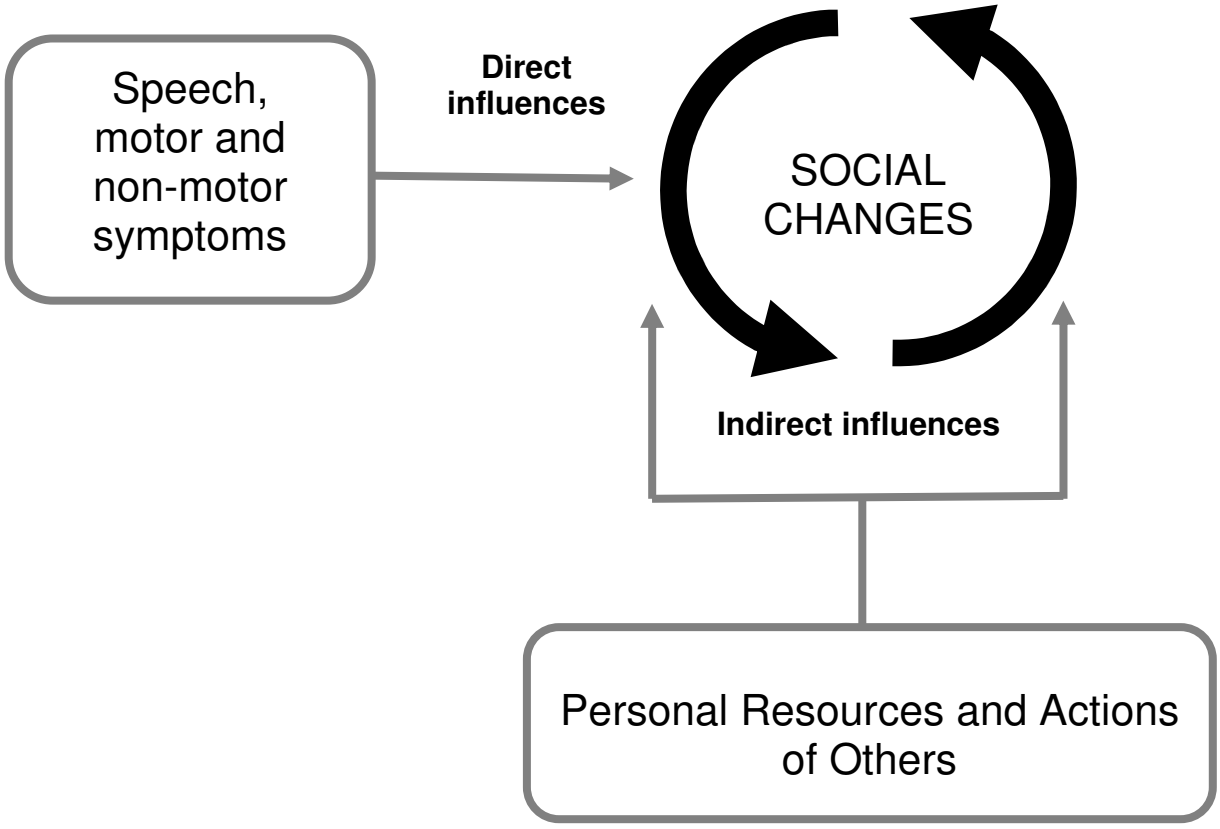
There was considerable variation between participants in terms of the balance between direct and indirect influences on change to their social lives. For P10, a big role was played by direct symptoms especially speech on restricting her activity and her account also emphasises the reactions of others. She had maintained a wide social network despite being severely speech-impaired. In contrast P38 described the central role of motor rather than speech symptoms in changes to her social life. She was determined not to let the responses of others affect her but did find that awareness of how PD might affect her undermined her confidence and prevented her from expressing her personality. For P64 physical symptoms were restrictive but her husband was also unable to walk far for different reasons and so travel and activity were limited by other factors of ageing in a family unit. In contrast to P10, her speech impairment, which caused similar difficulties sustaining a conversation, was much more directly implicated in P61 avoiding a lot of social contact and

becoming more solitary. These examples show some of the different ways that direct and indirect influences can bear on social change.

Social changes can take place in the context of PD in both positive and negative directions which are represented by the upward and downward curving black arrows. The symptoms of PD exert a negative or downward pressure within that system through interference with interaction and access to social opportunities. The personal resources of the person with PD and the actions of others can also exert downward pressure but can also support maintenance of and positive upward change in the social system. A key point in relation to the research questions is that speech impairment is likely to place a downward pressure on social functioning but is only one of a multiplicity of factors which can be present and which may exert pressure in both directions. The two constructs, direct and indirect influences, can be modelled as follows in figure 7-1:

Conceptually, the constructs are similar to aspects of the WHO ICF model (WHO 2002) in that speech, motor and non-motor symptoms align with the body, structure function/impairment and activity/limitation components, the personal resources and actions of others align with the personal and environmental components and the focus of investigation, social change, relates to the participation component. However, there is an emphasis here on

Table 7-1 Theoretical constructs influencing social changes



both the specific role of speech impairment and the relationship of this with other features of PD within the model. This will be discussed more fully in the next chapter.

7.8 Summary of chapter

This chapter presented the thematic analysis in the form of inter-related themes and sub-themes which were based on the most prevalent ideas emerging from the data through the accounts of the participants. These themes and sub-themes were related to the research questions, firstly as the role of speech impairment in changing social lives was explored in and secondly as the emergent themes allowed an interpretation of how various factors which are significant in the experiences of people with PD also impacted on social lives. It was evident from the entire data set and from individual accounts that the ways in which PD impacted on social lives was complex. Speech impairment was significant in these accounts but was one among a number of factors including mobility, behaviour of others and emotional response to the condition. The meaning of the themes and sub-themes was evidenced using data from participant interviews. Relationships between themes and sub-themes were explored and from this was developed an abstract theoretical understanding of the data which was based on the emergence of two related theoretical constructs which influence changes in social activity and social contact directly and indirectly. The qualitative data therefore supplemented the quantitative data by providing a context in which the quantitative data could be more comprehensively understood.

8 Chapter 8 Discussion

In this chapter the results of the study are interpreted and discussed and the contribution to knowledge is set out. The organisation follows the four themes which were identified in section 1.4 above. First, the scientific value of the study is explored with particular emphasis on the contribution of the quantitative investigation. Second, the methodological value of the study is explored with particular reference to the contribution of the qualitative data. Then the clinical implications of the findings are discussed and heterogeneity of individual cases is illustrated. Conceptual issues relating to the instruments for measuring severity of dysarthria are considered. Following this the contribution to developing theory is explored by evaluating the relationship of dysarthria to social capital and the relationship of the theoretical constructs generated from the interview data to a model of health and well-being and quality of life. Finally, the limitations and strengths of the current study are discussed, including methodological issues arising from the characteristics of the sample, and directions for future research proposed.

8.1 The scientific value of the project

In this section the results relating to the experimental hypotheses are discussed.

8.1.1 Effect of presence of dysarthria on social variables

Hypothesis 1

Comparisons were made between results for the control speakers and all participants with PD in order to test the hypothesis that presence of dysarthria will impact social variables negatively. Overall there was no difference in level of social activity or size of social network but there was a difference in social anxiety. This included increases to both discomfort in and avoidance of social situations in the participants with dysarthria arising from PD.

Overall levels of activity were comparable to unimpaired speakers reported elsewhere but high for both groups of dysarthric speakers compared to people with aphasia using the same measures (Cruice et al., 2006). This may have been influenced by the characteristics of the sample which had relatively high social and educational level and which had normal levels of cognition, anxiety, depression and apathy. (Sampling issues are discussed in more detail later in this chapter). Participants with PD in this study did have limitations on mobility for activities of daily living which participant accounts indicated did impact on social participation but which in this sample was not sufficient to influence the quantity of activity or size of network.

It is not surprising to find that a measure of discomfort in social situations is sensitive to presence of dysarthria. Miller et al. (2008) found that people with dysarthria and PD rated themselves less well as a communicator on dimensions of control, confidence, frustration, feelings of inadequacy and loss of

independence. They suggested that such feelings may lead to social withdrawal (which qualitative data have supported, as detailed above) and the quantitative measures here confirm this to some extent. IIS Frequency scales, which measure social avoidance, were significantly lower for people with PD and dysarthria. However, avoidance appears to be elevated only in specific social situations. In this study discomfort and avoidance were significantly affected for situations which involved initiating contact with others. Avoidance, but not discomfort, was also significantly affected for situations in which a positive statement about oneself is made. Situations which involved giving criticism, expressing an opinion or giving a compliment were unaffected.

Initiating contact may be a crucial communicative skill in building and maintaining social connections. Joining conversations, asking for information and help from strangers and friends are moments during interactions when there is particular focus on self-presentation and may be particularly sensitive social tasks for someone who has a lowered estimation of the adequacy of their communication. Other situations, such as expressing an opinion or giving criticism, may be less uncomfortable because the protagonist is likely to be already established in a conversation before offering such a contribution. Furthermore, some psychosocial dimensions are relatively impervious to change in speech and disease progression in PD (Miller et al., 2011) and it is hypothesised by these authors that there may be a difference between those dimensions that are close to the communicative act and those that are core traits of personality. It may be that willingness to express an opinion, criticise or

compliment are related to more stable perceptions of personality which are relatively independent of impairments acquired in or after midlife. Indeed, similar results were not found for people who stutter, a predominantly developmental communication disorder (Kraaimaat et al., 2002). Initiating contact is likely to be more influenced by changes in perception of communicative control and competence.

Among participants with dysarthria and PD, discomfort making positive self-statements was not higher than control participants but these situations were avoided. An explanation for this may be found in the qualitative data, as it is evident from the accounts of dysarthric speakers that there is frequently an expectation of negative evaluations by others. As greatest change in perceptions of self as a communicator before and after onset of PD centres on feelings of competence and control (Miller et al., 2008), in situations where a positive self-statement is appropriate speakers with dysarthria may be more conscious of dissonance between such statements and their self-perception. This dissonance may encourage avoidant behaviour. Detailed investigation of the mechanisms which govern situation-specific decisions to engage or avoid social contact in speakers with dysarthria is yet to be undertaken and so these are necessarily tentative comments.

Particular difficulty initiating contact may help to explain why level of leisure activity differed between participants with dysarthria and control participants. Groups based on activity are relatively stable in terms of membership and

provide predictable and familiar structures for socialisation. The supportiveness of others in accounts of change in the current study often refers to how this occurs in groups. Leisure activities within the SOCACT include a range of public situations which are likely to involve speakers in situations where they may need to initiate contact with others, such as going out to eat or to visit facilities or places. It is possible that speaking difficulties surrounding initiating interactions combine with physical limitations and other barriers to accessing these opportunities to reduce the number of leisure activities recorded.

Satisfaction with number of social activities was significantly lower in those with dysarthria and PD. This may reflect a greater importance for participants of leisure activities as a constituent of overall activity. Leisure activities were consistently much higher in number than informal or formal group activities but data on how participants valued each activity was not collected and so this cannot be confirmed or refuted. As overall number of activities did not differ between groups, reports of satisfaction may have been based on a more general perception of quality rather than quantity. Responses to this question more closely resemble the accounts of experiences of change in social life in that almost all participants with dysarthria expressed dissatisfaction despite wide variation in number of activities. This again highlights the importance of studying both the level and the personal experience of social participation (Yorkston et al., 2012; Poulin and Desrosiers, 2009).

Presence of dysarthria was not associated with difference in overall social network size or in constituent categories of the network either of importance or relationship type. Predictions about social network responses to chronic disease include vary as to impact on size. Litwak (1985) proposed that greater need for support would lead to increase in networks while Janssen (1992) argued that exchange theory predicts a decrease in network size because of the developing support imbalance between the focal individual and network members, difficulties maintaining activities and establishing new contacts. Kahn and Antonucci (1981) predicted that the network structure of the convoy model adopted in this study would remain stable initially but with increased level of activity in the inner circle as close family become most active in providing support to a person following diagnosis. They then predict a decline in network size over time as less central members lose contact. Tijhuis et a.l (1998), in a large study of chronic disease, did not find that participation in voluntary organisations declined with disease duration and Pennix et al. (1999) also found that although feelings of loneliness increased and instrumental support decreased during some chronic illnesses, social network size was not affected by illness. It is not therefore inevitable that presence of complex chronic conditions like PD necessarily leads to social network decline although other features of network support may be affected and network size does decrease in some individuals. In older populations, including the sample in the current study, consequences of illness may be mitigated by age as existing relationships have been established over long periods and may be more robust to change (Pennix et al., 1999).

The findings for social network size in the current study and reported elsewhere in relation to presence of dysarthria are in contrast to those reported for effect of aphasia on social variables where networks in general, and number of friends in particular, decreased (Northcote and Hilari, 2011; Vickers, 2010; Dalemans et al., 2007; Cruice, 2006). This suggests that the impact of communication impairment in aphasia in relation to quantitative aspects of social participation is greater or may be harder to adapt to than in dysarthria. The impact of dysarthria on the individual should not be underestimated however. It is clear from accounts of speakers with dysarthria that it can have very profound effects, but as a group and considering the preservation of social networks and activity, the challenges posed by dysarthria are in some respects different to those of aphasia. Aphasia is typically acquired suddenly, for example following stroke, and is most commonly non-progressive. People with aphasia are likely to experience some improvement from baseline impairment level following onset. In contrast, changes to speech in PD are gradual but degenerative. From the point of view of both speaker and conversation partner, aphasia can present a sudden and profound challenge including significant unseen impairments such as comprehension impairment. This means that from the point of view of familiar interlocutors (those who are likely to be listed in social networks), dysarthria at onset may be less disruptive although this may not be the case over the longer term as communication is progressively more impaired. Listeners may be able to adapt to gradual changes in speech before the communicative support demands of interactions threaten continuity of the relationship. This would suggest that, on aggregate, greatest difficulty is likely to

be encountered with unfamiliar listeners and novel social situations which is supported by the results of this study. Evidence from studies which have investigated effects on social variables of aphasia specifically rather than stroke more generally (Dalemans et al., 2010; Cruice et al., 2006) suggest that communication impairment is particularly important as a factor in quantitative changes to social life. This will now be discussed in relation to severity of dysarthria.

8.1.2 Effect of severity of dysarthria on social variables

In this section the effects of severity of dysarthria on social variables are discussed. The hypothesis that more severe dysarthria would result in negative impact on social variables was first tested using intelligibility as a measure of severity and then using motor speech impairment (FDA). Issues relating to differences between these measures are addressed following discussion of the results.

Differences in intelligibility were not associated with differences in social activity, social network size or discomfort in social situations. Cumulative frequency of activity and avoidance of social situations involving initiation of contact were adversely affected by intelligibility. This suggests that intelligibility is only weakly predictive of quantitative social variables and this finding is consistent with others for the impact of dysarthria on social participation which have used intelligibility as a measure of severity (Miller et al., 2006, 2008, 2011; Dickson et al., 2008; Walshe and Miller, 2011; Brady et al., 2011).

In contrast to the weak effect of intelligibility, motor speech impairment, represented by scores on the FDA, had significant effects on social activity, social network and social anxiety. Severity of motor speech impairment did not affect overall level of discomfort in social situations but did affect discomfort when initiating contact. However, avoidance of these situations was not affected. The results therefore show that there is a general effect of dysarthria on discomfort and avoidance of initiating contact and a specific effect of dysarthria severity on discomfort when initiating. The increased discomfort with more severe dysarthria does not appear to translate into avoidance behaviour and this suggests that avoidance may result from a combination of factors including but not restricted to speech. The range of factors both intra and interpersonal described in the qualitative data as relevant to change in social behaviour supports this interpretation. Post hoc testing showed that levels of discomfort found in the group with mild dysarthria were not different from those of the control participants and this may indicate that there is a threshold for degree of motor speech impairment to become significant for impact on social anxiety which is discernible at group level.

Although overall level of social activity was not affected by severity of dysarthria, both leisure and formal group activities were adversely affected and comprise a large proportion of total activity. Preservation of level of informal group activity may reflect features of this type of activity. Informal family and friendship social occasions may in general be supportive towards members; reactions of others and situational pressures may have less impact on

participation in these situations. Established patterns of meeting and longstanding relationships may place greater social obligations on attendance which are not present to the same level in leisure or formal group occasions. As the groups did not differ on other PD related variables it unlikely that these account for the differences in activity levels so while the qualitative data indicate that other factors contribute to reductions in social activity the quantitative data suggest that deteriorating speech has a specific additional effect.

Cumulative frequency of activity and satisfaction with activity level were also affected by severity of dysarthria. Reduction in frequency of activity shows that as the range of activities declines this is not compensated for by increased frequency of the remaining activities. There is an overall attenuation of activity. Indeed, effect size for reduction in frequency is approximately twice that of reduction in range of activity. This picture of activity loss is consistent with qualitative data findings as is the lower satisfaction with level of activity expressed by many participants.

Overall social network size showed a significant reduction in the group of speakers with more severe dysarthria. This was consistent across all circles of closeness/importance within the network although the greatest effect size was seen in the outer circle. This bears out Kahn and Antonnucci (1981)'s prediction, regarding the convoy model of social networks, that losses would take place after an initial period of stability and that network members most likely to be lost are those who are least proximal to the focal individual. Studying

types of relationship within the network, it is evident that close family members are more likely to remain within the network than friends or other relatives. Together, the patterns of change suggest that friends and relatives who are least central to the focal individual are more likely to leave the network. It is worth noting that the range of network sizes in all groups was very wide, emphasising the degree of individual variation that is present in this data and which concurs with qualitative accounts where speech severity is not strongly linked to social participation.

Post hoc testing for both social activity level and social network size and composition showed that the participants with less severe dysarthria did not differ from the control group on these variables. This suggests that the specific effect of dysarthria on social variables in this sample became evident at a threshold level of impairment. The accounts of people with dysarthria in the current study and elsewhere show that the qualitative experience of social participation is typically impacted at all levels of dysarthria. However, where motor speech was only mildly impaired in this sample it did not significantly affect social anxiety and structural features of social support (activity level and network size) at group level. There are similarities, therefore, between the effects of moderate dysarthria and those of another communication disorder, aphasia, on social variables.

The dependent variables in the current study measured different aspects of social functioning but it is logical to suppose that they are also related to each

other. For example, many social activities take place with members of social networks. Involvement in groups and extent of social networks are both used as indicators of social participation within the wider concept of social capital as discussed in section 2.7 (Giordano and Lindstrom. 2010; Ferlande,r 2007; Harper, 2001; Rose, 2000; Lochner, Kawachi, & Kennedy, 1999). Avoidance of social situations is also plausibly linked to changes in social networks and activity, since a preference for particular types of social situation may prevent participation in activities and act as a restraint on establishing new contacts. Impact of dysarthria on social participation is complex and multidimensional (Miller et al., 2006; Dickson et al., 2008; Walshe and Miller, 2011; Brady et al., 2011). In the current study discriminant function analysis revealed that there were significant relationships among the main dependent social variables. Two functions emerged which together discriminated the groups in the study from each other. The first function loaded most strongly onto structural aspects, social network and activity and discriminated degree of severity of dysarthria. The second function loaded most strongly onto social anxiety, both discomfort and avoidance, and discriminated control participants from those with dysarthria.

8.2 The methodological value of the project

8.2.1 Accounts of social change

A limitation of quantitative tallies of social activity and network is that how people feel about their social experience and relationships is missing from such data and these are factors which are likely to influence behaviour substantially.

Quantitative data can be enriched, as in the current study, by analysis of sub-categories of activity and social network. This richer data may shed some light on issues of value to the participant, for example by giving some indication of the relative importance of different members of the network to the focal individual. However, such categorisation, while it provides a closer view of group characteristics, necessarily eliminates much of the individuality of the felt experience. Existing research suggests that participation in everyday activities is a multidimensional not a uni-dimensional construct which is difficult to capture in a single measure and that subjective importance of participation in everyday activities is relatively independent of mobility, health status, depression and fatigue (Yorkston et al., 2012). In this and other studies it is clear that, while speech is a concern for people with dysarthria and has reported impact on social participation in a variety of ways, other factors such as physical and mobility impairments may be an even greater concern both in combination with and in addition to speech impairment (Walsh and Miller, 2011). For this reason, qualitative investigation of the experience in social situations of speakers with dysarthria is helpful in drawing out a sense of how and why changes happen in social lives. This has already been carried out in relation to speakers with PD and other neurological conditions (Miller et al., 2006; Dickson et al., 2008; Walsh and Miller, 2011; Brady et al., 2011). There are many areas of convergence of the qualitative data from the current study with the published findings which include changes to speech, impact on conversation and interaction, impact on social life, coping strategies, behaviour of others and

emotional responses to the situation. Convergence with and difference from these findings are addressed in the following section.

The changes to speech described in the current study and which include loss of volume, articulation impairment and loss of normal intonation are characteristic of people with dysarthria and PD (Duffy, 2005) and are similar to those found by other qualitative reports (Miller et al., 2006; Walsh and Miller, 2011). Such changes contributed in this sample to loss of intelligibility also found by other studies (Miller et al., 2006; Walsh and Miller, 2011; Brady et al., 2011). There is also a degree of convergence in the importance which speakers place on the consequences of speech changes for social interaction rather than on the detail of changes to speech dimensions. Further similarities in the ways that speech impairment manifested were noted across this and other studies in terms of variation in speech performance depending on situation and speaking task (Miller et al., 2006; Brady et al., 2011).

A concern common to all studies reporting on the impact of dysarthria is the way that the behaviour of others, listeners and conversation partners, affects the speaker with dysarthria. As in this study, other studies have found a perception among some speakers that their difficulties cause them to be left out of conversations resulting in them becoming less motivated to attempt to participate (Miller et al., 2006; Brady et al., 2011). The behaviour of others was sometimes seen by these participants as a barrier to successful communication but also sometimes seen as supportive and this has been found elsewhere

(Walsh and Miller, 2011). Sensitivity to the reactions of others and perceived negative evaluations by them was found in the current study and in other people with dysarthria (Brady et al., 2011).

Ways of managing conversations to deal with the consequences of dysarthria found in the current study are also reported more generally. Some participants self-limited their involvement in conversations by adopting a more passive role, avoiding demanding situations and hiding their symptoms from others in this and other studies (Miller et al., 2006; Walsh and Miller, 2011; Brady et al., 2011). Impact on sense of self and changes to life roles are also reported by Walsh and Miller (2011) and Brady et al. (2011) and described by participants in the current study and in addition there is evidence that some participants manage their social presentation to align their expectations with changed capabilities.

In the current study the focus of questioning during interviews resulted in a body of data relating to change in life participation as opposed to changes in communicative participation. Where studies have addressed the impact of communication change this has resulted in very similar themes emerging from the data which suggests that from the point of view of the speaker communication is central to life participation. Walsh and Miller (2011) reported on life changes which included role changes at home and work, loss of leisure activities and friends and reduced possibilities for interaction, all of which were described by participants in the current study. Loss of a sense of independence

and loss of confidence are associated with reduced social engagement here and elsewhere (Miller et al. 2008, 2011). A difference in the data reported here is that as well as loss of activity and quality of experience there was some evidence showing that people with dysarthria and PD strive to maintain where possible activities that they value, making adaptations to the nature of their involvement where necessary and regarding this in a positive light. Participants also reported acquiring new activities to replace others, particularly physical activities which their mobility impairments restricted them from carrying out, and finding new opportunities for social contact. There was a sense that social activity and interaction was altered and in many examples reduced but that change was not entirely negative. The personal approach to these difficulties was cited as an important factor, the desire to remain independent or to avoid self-pity was expressed as a motivator towards positive change. There is evidence from some participants of determination to live life as fully and independently as possible, to accept and not hide their symptoms, also found by Miller et al. (2006).

The concerns of and experiences of the participants in the present study in relation to changes to social life share many similarities with those of other people with dysarthria both with PD and other aetiologies. Although the data from this study revealed some positive change and affirmatory life approaches the impact of speech and other aspects of PD on social life was complex but commonly negative.

An important benefit of this study was that both quantitative and qualitative methods were combined. As stated above, this allows the strengths of quantitative data to be enriched by the accounts of the participants, preserving in the individuality of the data the meanings for each participant as well as the generalities of the group findings. The approach to the mixed methods research design taken was that the results from the participant accounts were intended to help with clarification of the quantitative data. This approach offers greater validity to the findings in general by providing a complementary perspective but also in particular, where there is convergence between the two data sets. It has already been argued that in many respects there is convergence between the qualitative data from this study and from other studies in which the impact of dysarthria has been investigated. It is further argued that there are specific ways in which the quantitative and qualitative findings of the present study are aligned.

Both sets of data demonstrate evidence of lessened satisfaction with social activity. This is very clearly seen in the quantitative findings where presence of PD with dysarthria was highly significantly associated with dissatisfaction with social activity in comparison with non-neurologically impaired participants (odds ratio 6.8). Dissatisfaction with social activity was also expressed in the accounts of many participants in terms of negative changes and loss of range of social activity e.g.

P11: I mean at one time we were here there and everywhere but now…
P5: …well we haven't got as much of a social life these days I must admit

The prevalence of accounts such as these was high with a large majority of participants expressing similar points (30 where n = 43). These accounts bear out the questionnaire data, providing a degree of triangulation of the findings, but additionally help in the interpretation of those findings. It was suggested above that data relating to dissatisfaction with social activity might be partly explained by participants interpreting the question as relating to quality as well as quantity of experience. Examples such as these show that the participants are referring to quantity of social activity being reduced. They are not simply transferring a perception of reduced quality of the experience to the quantitative domain, although perceptions of reduced quality are also expressed at other points. A further strength of combining qualitative accounts with quantitative data is that the range of causes of change to level of activity cannot be accurately assessed without them. These accounts and others are also consistent with the findings that frequency of activity may be significantly impacted by speech impairment. Higher prevalence of dissatisfaction with quantity of social activity among those participants with more severe dysarthria further supports the findings that moderate dysarthria negatively impacts social activity in this sample of speakers.

The participants' accounts provide an interesting view of the quantitative data relating to social anxiety. Both discomfort and avoidance were higher in the All PD group than in the control group but the differences were specific to

situations in which initiation of social contact was required. Many speakers gave accounts in which avoidance of social contacts or new interactions were described and attributed to negative changes to speech or which expressed a concern that focussed on the impact their speech might have on non-familiar listeners.

P58: on a one to one basis I'm usually a bit hesitant with strangers (.) not so bad with people I know well
P43: new acquaintances might wonder why I hesitate in speech a bit

A variety of situations were described which necessitated contact with new conversational partners such as queuing at the shops, attending a wedding, work-related meetings and large social gatherings which were not restricted to the close family or friendship circle. Some participants did identify an emotional response to novel interactions which revealed that they did experience some discomfort:

P17: …if there's somebody else or somebody in the queue happens to speak to you…there's a sort of nervousness in a way
P64: … it makes me feel apprehensive about going out (.) meeting people

Typically, however, discomfort in these situations was not described directly but expressed through reference to accompanying feelings of conspicuousness and embarrassment or loss of self-confidence which affected many participants. In some instances participants touched on their discomfort in challenging social encounters through self-deprecation e.g.

P18 – obviously we know the two people who are getting married (..) <um> but I'm probably being a bit silly

Many accounts, therefore, while indicating that avoidance of new social encounters did take place did not explicitly verbalise the discomfort which the questionnaire data revealed. Instead, the accounts show that the discomfort recorded through the IIS results reflected a range of emotional experience and a range of reactions to those experiences. This is helpful in that it enables the researcher to see that the global construct 'social discomfort' captures a relatively nuanced reality and exposes differences in the way that participants orient to their subjective experiences.

8.3 The clinical value of the project

In this section the contribution of the project to clinical practice is considered. It was an aim of the project to identify measures suitable for use with dysarthric speakers. This included the question of whether measuring social functioning offers a useful insight into the situation of someone living with dysarthria and the value of the specific measures chosen. The variation in participants' social profiles and the relationship between measures of speech impairment and social functioning is discussed. Consideration is given to the utility of different types of measure for assessing severity in dysarthria and finally the findings are related to the wider disability discourse.

8.3.1 Utility of measures

As Yorkston et al. (2012) state, there is a need to measure the level of activity as well as reactions to it. The results of this study show that both the quantitative measure of social activity (SOCACT) and the quantitative measure of social network (the convoy model) are sensitive to change brought about by

increasing motor speech impairment in this sample. In addition, the measure of social anxiety (IIS) was also demonstrated to be sensitive to presence of dysarthria and a global indicator of satisfaction with social activity was sensitive to presence and severity of dysarthria. There is thus an argument for incorporating structural measures of social functioning and measures of social anxiety and satisfaction into assessment of clients with motor speech disorders. Discriminant function analysis indicated that there is an underlying dimension of social functioning which represents a combination of network and activity variables. Therefore, both activity and network data should be collected. It cannot be assumed that either will act as proxy for the other. These measures would complement the existing measures e.g. the Dysarthria Impact Scale (Walshe et al., 2009) which focus on other psychosocial dimensions. Given the indications that there is a threshold of impairment severity beyond which there is a risk of erosion of social activity and network it would be desirable to collect data on social activity and network at first diagnosis and monitor periodically thereafter. As speech impairment progresses, those contacts and activities most at risk could become the focus of intervention which is directed at supporting the maintenance of relationships.

8.3.2 Heterogeneity

Previous findings have shown a lack of relationships between measures of intelligibility and social participation (Miller et al., 2006; Walsh and Miller, 2011; Brady et al., 2011). In this study, variation in levels of social participation was very wide in both control and speech impaired groups. To illustrate the lack of

simple correspondence between severity of dysarthria and social impact two cases are presented which differ in level of speech impairment and social involvement. These cases underscore the importance of studying the individual as well as the group when considering the impact of communication disorder on social participation.

P10 (female) and P8 (male) both had relatively early onset of PD at 49 and 50 respectively and at the time of data collection were of similar age. Both self-rated themselves as moderately limited in relation to activities of daily living (PADLS score of 3). However, intelligibility levels were very different, P10 - SIT 30%, P8 – SIT 97% and motor speech impairment also differed greatly, P10 – FDA 4.6, P10 - FDA 7.2. Severity of dysarthria was not predictive of differences in social variables. P10 had a social network total of 38 and P8 a total of 16 (group mean 27). Composition of the networks also differed. Family and friends comprised 84% of P10's network but only 50% of P8's. Although overall number of activities reported was similar (SOCACT total for P10 = 20, P8 = 16) proportion of solo activities was much greater for P8 (38%) than P10 (15%). Despite having much better preserved speech P8 experienced much more discomfort in social situations (IIS-D 105) than P10 (IIS-D 78) (group mean 72.9) and avoidance of social situations was much greater (IIS-F 89) compared with P10 (IIS-F 112)[4] (group mean 99.1). Both P8 and P10 described physical as well as speech limitations on their ability to participate and, for both, the onset and course of their PD had led to significant changes in the nature and

[4] Lower scores correspond to higher level of avoidance

quantity of their social lives. It is clear from these examples that degree of speech impairment was not related to the overall dimensions of their social lives and their feelings of anxiety in social situations. Although group differences related to severity of motor speech impairment on quantitative measures of social participation have been observed, it is important to keep in mind, if contemplating any clinical intervention, the multidimensional nature of social participation and the variation that can exist on an individual level.

8.3.3 Measuring severity of dysarthria

A question that must be addressed is why social variables should be unaffected by differences in intelligibility in dysarthric speakers but negatively impacted by differences in motor speech impairment as measured using the FDA. Intelligibility has been investigated in relation to perceptions of speakers with PD and other causes of dysarthria (Miller et al., 2007; Walshe and Miller, 2011; Dickson et al., 2008) and these studies have not found a relationship between intelligibility and impact on social participation. Where intelligibility has been investigated in relation to scores on psychosocial dimensions with focus on self as a communicator, how participants perceive communication to have changed and level of intelligibility are only weak-moderately correlated (Miller et al., 2008) As intelligibility worsened in a section of the same cohort, the strength of this relationship did not increase (Miller et al., 2011). There is therefore both qualitative and quantitative evidence that intelligibility is not strongly related to impact on participation, while it is clear from the accounts of people with

dysarthria, including those with PD, that they perceive dysarthria to make a real contribution to deterioration of communication and social life.

Some explanation of the weakness of intelligibility to predict impact on social variables is needed. One possibility is that social participation is affected by such a wide range of variables, including communication, mobility, mood and cognition, and is itself so varied in terms of how people determine their satisfaction with it, that the impact of speech alone is insignificant. However, the accounts of speakers with dysarthria and the effects of motor speech severity observed in the current study do not support this.

Another possibility is that intelligibility does not measure the most salient dimensions of speech from the perspective of the speaker. Intelligibility, whether measured using an overall estimation or using item identification, is the result of listener, medium, task and speaker variables (Kent and Kim, 2011). It is possible that the optimal assessment conditions which typically apply in research studies result in maximising performance and not accurately reflecting underlying speech production capacity. In this study participants did not have to produce speech to meet a communicative need arising in a natural environment but read sentences aloud. This reduces cognitive demand and may enable speakers to make compensatory adjustments to speech more easily, realising acceptable phonetic targets through different combinations of acoustic features (Hazan and Markham, 2004) and contributing to a ceiling effect where sensitivity of intelligibility measures to milder dysarthria is lower (Yorkston and

Beukelman, 1978). Impairments in speed, strength and accuracy of articulator movements which result in changes to the accuracy of speech sounds therefore do not necessarily have a large effect on intelligibility. The resulting intelligibility score will not reflect all aspects of speech production and may not reflect the degree of impairment to different dimensions of speech. For example, Nishio and Niimi (2006, 2001, 2000) found that syllable repetition alternating motion rate declined while intelligibility remained good in dysarthric speakers with amyotrophic lateral sclerosis and concluded that it was sensitive to change in articulation in the early stages of degenerative neuromuscular dysfunction in a variety of types of dysarthria. Intelligibility measures certainly will not reflect the speaker's individual reactions to the impairments or to the effort needed to make compensatory adjustments which itself can have a detrimental effect on communicative participation (Miller et al., 2006).

Factors which distance intelligibility scores from underlying motor speech impairment are less applicable to the FDA. Because the output of most FDA tasks does not have any semantic content that the listener must recover, or the task does not require recovery of the content, it follows that word- and sentence-related contextual support does not influence the result. Compensatory adjustment is less relevant to FDA tasks because they are mostly designed to tax unidimensional, metathetic aspects of speech production, such as volume or articulator excursion, whereas intelligibility is the result of combining and coordinating many aspects of speech. This reduces the ecological validity of the FDA tasks but may help to account for the wider range

of severity in the FDA scores compared to the intelligibility scores in the current study. It may be argued that because the FDA contains non-speech oromotor tasks that it may be indexing more general deterioration of motor systems resulting from PD and therefore not specifically measure speech impairment. The lack of observed differences in the general mobility scores and the disease duration scores for the two groups of dysarthric speakers (divided using the FDA measure) suggests that this is not the case while the difference in the same groups on the intelligibility scores increases the likelihood that the FDA scores are indexing speech, not solely motor, impairment.

The use of nonspeech oral movement tasks to assess and particularly to treat dysarthria has been questioned following evidence that the neurological control of oral movements is task specific (Ziegler, 2000; Weismer, 2006; Bunton 2008). Although this evidence is persuasive in some respects, Bunton et al's review of studies relating non-speech to speech measures revealed that the typical measure of speech production used was intelligibility which is arguably a measure of disability rather than impairment. The global nature of intelligibility scores in relation to speech production means that such studies do not show whether and how participants may have recruited relatively unimpaired areas of the speech production system to achieve intelligibility. In this study, non-speech items within the FDA were strongly correlated with the speech-based items (Pearson's $r = .79$, $p = .009$) which suggests that the scores are related to an underlying motor speech impairment. The suggestion that this might be the result of a third variable such as overall motor deterioration is not borne out by

correlation with the general mobility scores taken form the PADLS (Spearman's *rho* = -.26, *p* = .17). The question of how speech-like non-speech tasks are is relevant to this discussion and is currently unresolved. Anatomical evidence for hemispherical separation of speech and non-speech task control using brain imaging techniques has been proposed (Horwitz et al., 2003; Wildgruber, Ackermann, & Klose, 1996) but the tasks used in these studies obscure the speech-nonspeech distinction. Wildgruber et al. (1997) used covert speech tasks which obscure the extent to which overt speech production shares substrate with nonspeech oral movement during motor output. Horwitz et al. (2003) used an oral motor task consisting of 'self-generated laryngeal and oral articulatory movements and associated sounds' (p1869) and so it is not clear to what extent these resembled speech motor movements in each participant. Whilst there is now a clear justification for using speech-based assessment techniques especially for planning intervention, further data examining the relation of individual FDA items to other measures including acoustic indicators of dysarthria is needed.

8.3.4 Considering the findings in relation to the wider field of disability

The findings of this investigation relate to a specific population of people with Parkinson's disease and dysarthria. Where communication impairment was present there was loss of social network membership, of social activity and increase in social anxiety. Participant accounts suggested that these were inter-related – loss of activity reduces network contacts, anxiety about communicating reduces opportunities to make use of networks, lower

satisfaction may reduce number of attempts to socialise. These findings are consistent with others from the field of communication disorders (Northcott and Hilari, 2011; Cruice et al., 2006; Hilari and Northcott, 2006; Kraaimaat et al., 2002) but potentially have wider implications for other populations with communication needs.

There is evidence that populations with learning disabilities also experience difficulties with social inclusion and a danger that factors such as social and economic disadvantage have a compounding impact on health. Emerson and Hatton, (2007) found that a large percentage (31%) of the increased risk to health in young people with learning disability was attributable to differences in socioeconomic resources and social capital. More socially-oriented approaches to intervention have been called for (Williams and Heslop, 2005) and the effectiveness of providing interventions directed at supporting connections between service users and services of various kinds was demonstrated by Raghavan, Newell, Waseem, & Small, (2009). Social network recording has proved a valuable tool for understanding aspects of social inclusion, a concept closely related to that of social capital (Pawson, Raghavan, Small, & Studies, 2005). The findings of the present study therefore align with evidence accumulating in the field of learning disability but also offer an additional contribution which could help to understand the mechanisms of exclusion better. For example, the role of communication ability in initiating, supporting and undermining the maintenance of those relationships which underpin social exclusion and inclusion appears to be significant. Specific issues that could be

explored further within the learning disabled population are what kind of communicative strengths or needs are most influential in building, maintaining and eroding social networks and what kind of social anxiety profile people with learning disability display.

8.4 The theoretical value of the project

In this section the discussion concerns two aspects of the study in which existing theoretical concepts can be enlarged on the basis of the findings of the investigation. First, the relationship of the theoretical constructs derived from the qualitative data to the WHO ICF framework is discussed and the discussion is extended to consider the findings in relation to the concept of quality of life. Second, the extension of understanding of dysarthria within the domain of social capital is considered.

8.4.1 Relationship of theoretical constructs to ICF framework

The theoretical constructs which underlie the thematic framework which emerged from the data from the current study reveal two major areas of influence on social participation in speakers with dysarthria and PD. There are 'direct' influences which arise from impairments which are described by participants and which have a typically negative impact on the quality and likelihood of communication in social situations and on the ability and willingness to access social situations. Here it is important to stress that speech impairment was only part of the impairment profile which was described. Problems relating to mobility, physical functioning and non-motor aspects of PD played an important role in the overall impact of the disease on social

participation. How these other factors interact with speech impairment and how prominent speech impairment is among concerns regarding impact is likely to vary at different times during the course of a progressive and degenerative disease such as PD (Maton, 1988).

There are also ‘indirect’ influences on social participation which may be both negative and positive in relation to change in social participation. By ‘indirect’ is here intended that these are factors which relate to the psychological response of the individual with dysarthria to their situation and also the responses of others including any institutional barriers or facilitators to participation. While both personal and others’ responses to the challenges posed by dysarthria are often described as having a variety of adverse effects on quality and quantity of social engagement it is in these areas that participants described attitudes and behaviours which were supportive of continuing social engagement and positive change. The theoretical model underlying the data therefore aligns with a biopsychosocial approach to modelling health such as the ICF (WHO, 2002). Direct factors in the current model can be understood in relation to the ICF components of structural and functional impairments and activity limitations. For example, disruptions to initiation of speech, medication-related inconsistency of movement and recruiting sufficient breath are impairments of speech production described here. Mostly, however, participants described activity limitations such as difficulty achieving normal volume, reduction in range of intonation, inaccurate articulation and loss of intelligibility. There is support from this data, therefore, for the relationship between the components expressed in part 1 of

the ICF model: Impairments in body structure or function impose limitations on activities which restrict participation in life roles.

Data from the current study also lend weight to the real influence of the ICF part 2 contextual components, the environmental and personal factors in that the indirect influences on participation described relate both to the situational variables and the behaviour of others when communicating with people with PD and the internal psychological and emotional response of the person with PD. The data also illustrate the influence of contextual factors on impairment and activity as well as participation. For example, speech production was likely to be worse in particular social situations and speaking situations and this led in some instances to avoidance of those situations. Personal factors could also influence speech, for example where additional effort was employed to raise volume. Environmental influences also had personal psychological consequences. Reactions of others were associated with negative emotions which led to participants curtailing social engagement. The data therefore support the structure and the complex interrelationships of components expressed in the ICF model. Quantitative measures of social participation in the current study also support the ICF distinction between concepts of capacity and performance. Speakers with mild motor speech impairment who all also reported a degree of difficulty with activities of daily living reported levels of social activity and social network comparable with those of a control group. The effects of PD lessened their capacity in these crucial areas but their performance as measured on these social variables was unchanged. Personal and environmental contextual

factors as revealed in the qualitative data may explain differences between capacity and performance as well as differences between quality and quantity of social participation.

The diagrams (figures 8.1 and 8.2) display the correspondences between elements of the ICF framework and the theoretical constructs which underlay the qualitative data in the study. Figure 8.1 identifies the ICF components which correspond to constructs within the theoretical model. In figure 8.2 the ICF model is presented and areas and relationships which are also represented in the theoretical model are highlighted. As can be seen in figure 8.2, the 'direct influences' identified in the current study correspond to the body structure and function component of the ICF framework. These direct influences, including speech and mobility impairment, exerted a generally negative influence on the social lives of participants which is represented by the black arrow connecting to the participation component of the ICF framework. The 'indirect influences' on social behaviour identified in the current study include both the response of the participant to their predicament and also the behaviour and attitudes of others. These are represented as separate components within the ICF framework, the personal and environmental contextual components, and these too bear on the participation component but may exert facilitative influence as well as negative. The data from the current study therefore help to validate the ICF framework in general but also the complexity of the relationships between components.

Figure 8-1 Correspondences between WHO ICF components (in red) and the model of the theoretical constructs showing overlap between constructs within each model.

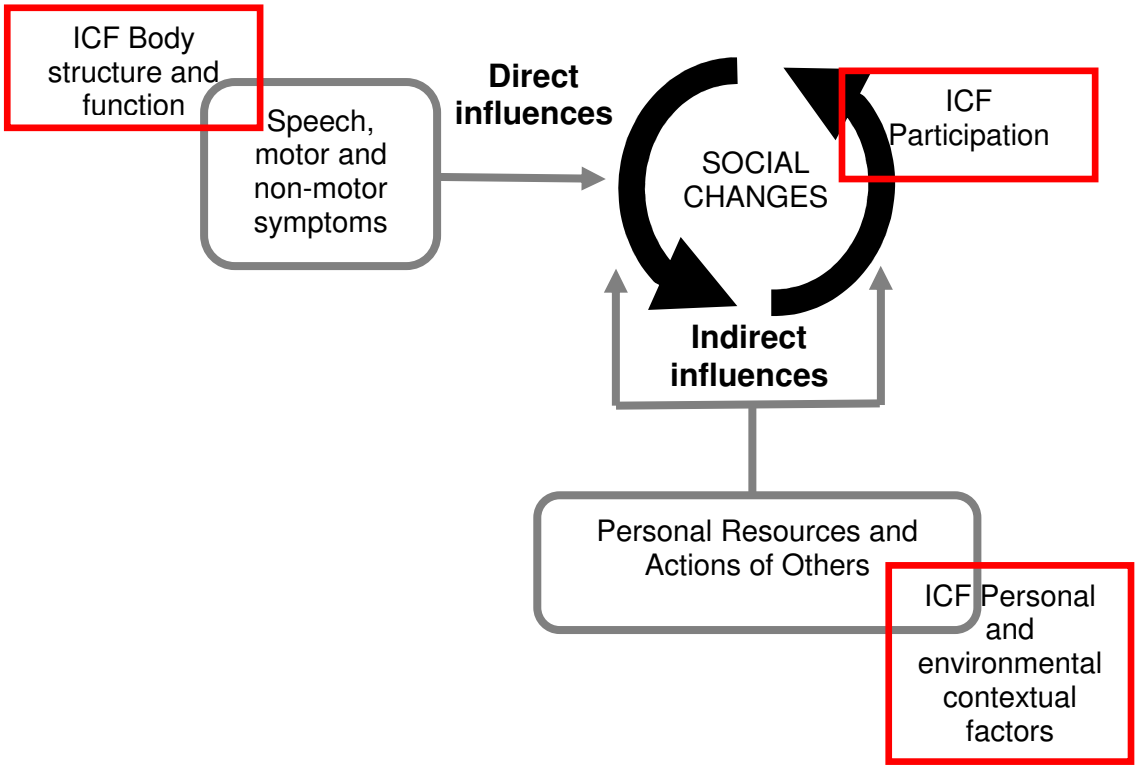
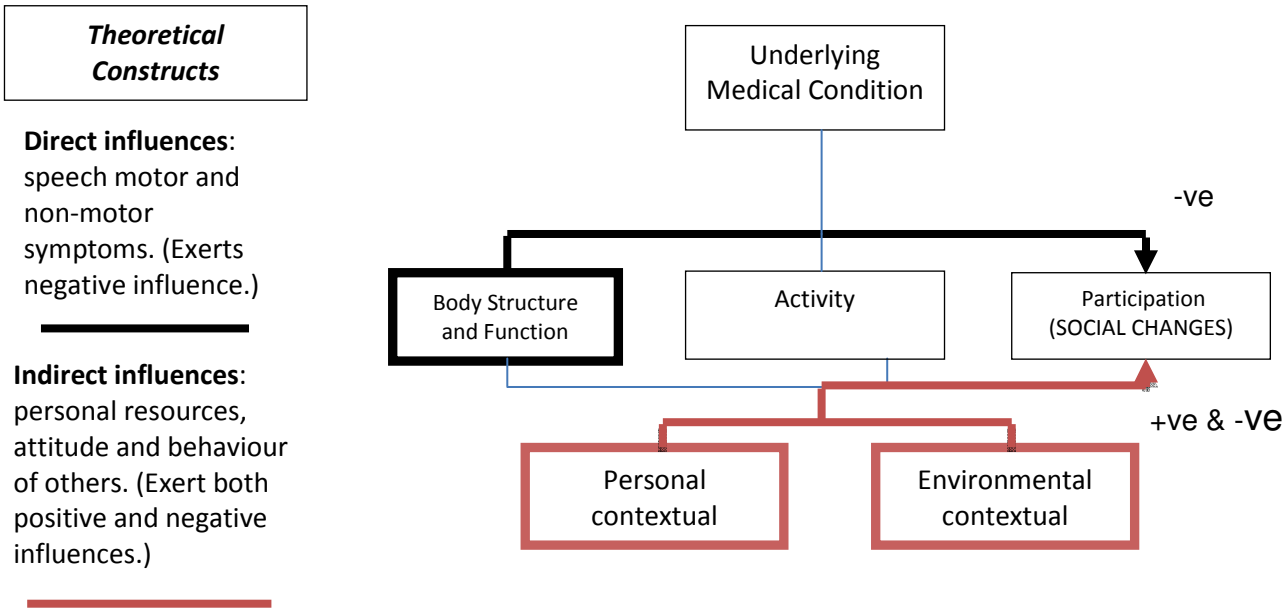


Figure 8-2 Mapping the theoretical constructs (left) on to the WHO ICF framework (right).



8.4.2 Quality of Life

Satisfaction with social functioning is a core aspect of quality of life across many definitions of the construct (Bowling, 1995). Some discussion of the relation of the findings of the current study to the concept of quality of life is therefore warranted. Perception of quality of life in the patient is important in the management of PD as it provides the patient perspective about the extent of the impact of different types of symptoms. Health related quality of life (HRQL) is typically measured across a number of domains including social and leisure activity. Disease specific measures are desirable as they are likely to be more sensitive to change in the specific patient group and HRQL has come to be considered an important outcome measure (Marinus, Ramaker, Van Hilten, & Stiggelbout, 2002).

HRQL scales specific to PD include sections relating to communication (Hobson, 1999; Peto, Jenkinson & Fitzpatrick, 1995) but these sections are restricted to general aspects of speech such as ‘difficulty talking’ or ‘difficulty with speech’ and do not draw out the range of speech output difficulties which can occur in PD and which, as the current accounts have shown, impact on communication in different ways. Thus, the differing impacts of low volume, imprecise articulation and dysfluency are not accounted for in commonly used HRQL measures for PD. In comparison, the PD-39 (Peto et al 1995) includes a much greater range of fine motor tasks associated with limb control. Studies of quality of life in PD show that the disease does have a significant impact on social isolation (Karlsen, Larsen, Tandberg, & Maeland, 1998; Karlsen,

Tandberg, Årsland, & Larsen, 2000) but these studies do not discuss the possible links between speech symptoms and social life curtailment. Although attempts have been made to identify those symptoms of PD which have the greatest impact on HRQL, speech impairments have been ignored as a factor while there has been a focus on a multiplicity of motor, cognitive and mood symptoms (Muslimovic, Post, Speelman, de Haan, & Schmand, 2008; Rahman, Griffin, Quinn, & Jahanshahi, 2008; Schrag, Jahanshahi, & Quinn, 2000).

The accounts of the participants in the current study and earlier qualitative research (Walshe and Miller, 2011; Miller et al., 2006) show that dysarthric speakers with PD perceive changes of speech to play a significant role in affecting social life which is central to quality of life. Results from the quantitative investigations support these perceptions showing that more severe dysarthria has a specific and detrimental impact on social functioning. It is possible that the design of HRQL instruments plus the lack of attention to the variety of speech symptoms in research into how PD affects quality of life has resulted in the contribution of speech impairment to quality of life in PD being ignored. An attempt to rectify this situation should be considered when further studies investigating PD-related quality of life are considered.

8.4.3 Extending into domain of Social capital

The results described above, together with the outcome of the discriminant function analysis, indicate that severity of dysarthria may affect social participation in structural ways, through loss to social networks in particular. This is discussed here in relation to the concept of social capital where it is

argued that, in addition to existing theoretical frameworks for understanding motor speech impairment, dysarthria should now be understood within a new domain, that of social capital. In particular, dysarthria presents a challenge to the individual's ability to retain social capital and so poses a threat to health and well-being in a wider sense.

The challenges of defining the multidimensional concept of social capital have been discussed above (section 2.7). Although social capital has several generally agreed components, social networks, reciprocity and trust (Putnam, 2000) social networks are the core structural element (Ferlander, 2007) and are associated with a range of health benefits including mortality (Kawachi, Kennedy, & Lochner, 1997) and self-rated health (Rose, 2000, Kawachi, Kennedy, & Glass, 1999). The characteristics of networks have different consequences for health. Diversified networks which are characteristic of bridging capital are more beneficial than bonding capital (Ferlander 2007). The mechanisms by which social capital confers health benefits may be both psychological and behavioural. More diversified networks are associated with lower rates of depression (Erickson, 2003) and encourage greater awareness of health issues (Kawachi et al., 1999). Dense, informal networks are associated with better health. Greater embeddedness in social networks is associated with a higher sense of stability and well-being (Cohen and Wills, 1985).

The role of communication skills in creating and maintaining social networks has been described elsewhere (Phillipson et al., 2001).The negative impact of

communication impairment on the machinery of sustaining social capital in this sphere - building and participating in such networks, participating in other social activities and maintaining contacts within the social network - is therefore of concern to the persons affected but is also of more than individual importance. Social networks and activities provide opportunities for maintaining and even improving social cohesion and these opportunities are often mediated through spoken communication. The effects of higher levels of social cohesion are to be found in better health outcomes within developed economies such as the UK (Wilkinson, 1996; Harper, 2001). Thus, the interpretation that one places on one's own communicative competence, its effects on interactions and the responses of communicative partners may ultimately influence one's own health in other domains. Furthermore, if social activity and network levels fall for individuals, this would result in a net loss to social cohesion for the wider community. Evidence indicates that this may affect health outcomes for that wider community too (Wilkinson, 1996). It is argued, therefore, that monitoring for personal and social psychological thresholds for disengagement should be a priority for intervention, especially where communicative impairment is present

The health consequences of eroded social capital (Ferlander, 2007) suggest that the impact of dysarthria may go beyond the psychological and social aspects of participation and place an additional risk to the health of the person with dysarthria. This is a further reason for ensuring that intervention approaches are oriented towards goals relevant to satisfaction with social participation and to consider, in particular, ways of identifying threats from

communication impairment to bridging social capital as described above (section 2.7).

The findings of this study together with those for people with aphasia shed more light on the concept of social capital itself. They indicate that social capital should be considered vulnerable to acquired communication impairment and that communicative skills might be a dimension integral to the structural dimensions of social capital. Correspondingly, acquired communication impairment should be understood in terms of its impact on social capital and the consequences which may follow from that. While the findings of the present study shed some light on the relationship between communication impairment and structural social capital the implications for cognitive aspects of social capital have yet to be investigated.

8.5 Strengths and Limitations of the Research

The research process involved a range of investigative processes and tools, both quantitative and qualitative. These are reviewed here to identify measures and procedures which were most effective and contributed most positively to the research. The limitations of the study were principally those relating to some instruments used in the quantitative aspects of the study and the representativeness of the sample. Specific issues are described below.

8.5.1 Cognitive screening

The study screened participants for cognitive functioning to ensure that all participants were within the normal range. In addition, groups were compared

on this measure and all group differences were found to be non-significant indicating that cognition was not an important factor in differences on social variables. Furthermore, linear regression indicated that the contribution of cognitive scores to the variance of the measures of social network and social activity was very small in comparison to the contribution of speech impairment. Although the measure used (SPMSQ) was sufficient to remove cognition as a confounding variable, an alternative, such as the Mini Mental State Examination (MMSE, Folstein et al., 1975) or the Parkinson neuropyschometric dementia assessment (PANDA, Kalbe et al., 2008) could offer a more sensitive indicator of variation in cognitive ability among the participants. There are two issues which arise from this. First, the screening approach taken resulted in the selection of a cognitively high functioning group which is not representative of all speakers with PD. Second, the contribution of cognitive status to changes in social variables would be better assessed with a larger number of participants which could support a multiple regression analysis involving a range of factors including depression, mobility and apathy. In this way the relative contributions of speech, cognition, mobility and other factors to changes in social variables could be better understood.

8.5.2 Intelligibility assessments

The intelligibility assessment used in this study offers a single interpretation of intelligibility which, as discussed earlier, does not capture all dimensions of this construct. The results showed that intelligibility levels among participants were generally high which may have arisen from compensatory efforts by the

participants which mask their underlying impairment. This would help to explain the lack of relationship between intelligibility and social functioning. Greater differentiation of speaker ability may have been achieved by introducing a dual-task paradigm for assessment in which intelligibility is measured while a concurrent motor task is performed, approximating more closely the task demands of day to day speech (Bunton and Keintz, 2008). Furthermore, inter-judge reliability checking was based on a small number of judges (N=2) who transcribed all speakers. As Hustad and Cahill (2003) have shown, repeated exposure to dysarthric speech results in higher estimates of intelligibility. It is possible, therefore, that intelligibility levels of participants were slightly inflated.

8.5.3 Measures of social life

The two instruments chosen to measure social participation provide a view of two key aspects of social connectedness namely social network and activity and, in that they have also been used with other clinical populations, permit some comparison with other communication disorders. While also offering a degree of detail and a range of sub-categories of network and activity of theoretical interest, these two measures have a number of limitations. It is evident from the qualitative data that individual social activities should be considered in terms of importance to the participant and not merely the number or frequency of activities. The relationship between any specific activity and the social network of the participant should be quantified in order to understand the wider potential harm to the individual's social system were an activity to be lost. Furthermore, although importance of network relationships was coded in this

study more data could be gathered as to what underlies the level of importance which is attached to a relationship, for example degree of instrumental social support and emotional support. Both instruments would need further development to achieve this and the current separation of data collection using the SOCACT and convoy model of social network does not afford this. A combined approach which integrates the data sets would be desirable and in order to gain a comprehensive picture of the psychosocial consequences of PD and dysarthria both a quality of life measure such as the PD-39 (Peto et al., 1995) and the Dysarthria Impact Profile (Walshe et al., 2009) should be used.

This project was only able to take a cross-sectional view of social lives and thus the relationship between the quality of social experience and reductions in the quantity of social life could not be observed directly. A longitudinal study, documenting the course of social change alongside the progression of speech and other impairments would have the potential to capture more precisely the critical factors and events which lead to quantifiable changes in the social systems of speakers.

8.5.4 Sampling Issues

Results of the study must be interpreted with reference to the sample of speakers that participated. The sample is not representative of all dysarthric speakers or all people with PD and dysarthria but provides evidence that, within a restricted sample, social participation is negatively impacted by dysarthria in structural, quantitative dimensions as well as experiential, qualitative ways. The design and resources available for the study necessitated the use of a limited

sample and the characteristics of the participants recruited limits the extent to which the conclusions can be generalised. These points are expanded on below.

A central aim of the project was to isolate the effect of dysarthria on specific variables of social participation. Dysarthria has a wide variety of manifestations and is typically accompanied by multiple and complex impairments arising from underlying aetiologies which affect many aspects of functioning, such as PD, multiple sclerosis, motor neurone disease and stroke. Selection of a single aetiology was therefore useful in identifying a potentially more homogenous group of participants than would have been the case if multiple aetiologies and non-progressive conditions had been considered. Nevertheless, within PD there is much variation in presentation of motor and other symptoms including speech and so the sample still contained a range of individual disability profiles. Therefore, in order to minimise the confounding effect of many variables, exclusion criteria were applied which ruled out of the study people with abnormal levels of cognition, depression, anxiety and apathy. Thus the sample represents, on these dimensions, a relatively high functioning group from the population with PD. It would be anticipated that where cognitive impairment and clinically relevant levels of depression and anxiety are present there may be additional and interactive effects on social participation, although perception of self as a communicator is only weakly associated with cognitive status (Miller et al., 2008; Miller et al., 2011). However, a design which factored all of these variables as well as motor performance and speech would, to achieve a good

level of statistical power (Cohen's recommended .8) for an expected medium effect size, require a minimum of 100 participants (Field, 2009). It would be advantageous to extend the research to investigate the full range of individuals with PD to see whether effects of motor speech impairment also occur where these other impairments are also present.

Recruitment of participants through support group networks may also have influenced the profile of the sample where group membership is not representative of people with PD as a whole. This is of importance because evidence shows that social network composition varies with age, gender, socioeconomic status and education (Tijhuis et al., 1998). Membership of the support organisation is large among people with PD but membership characteristics of the support groups may have biasing effects on the study and this is considered here.

In terms of gender, there were unequal numbers of males and females in the study and evidence suggests that illness support groups contain greater numbers of females than males (Deans et al., 1998). However, this was not reflected in the volunteering rate for this study and the ratio was representative of gender distribution in people with PD (Van den Eeden et al., 2003; Wooten et al., 2004). The average age of onset of PD within the sample was also representative of the wider population of people with PD (Twelves et al., 2003) although the spread of the data indicates that a higher proportion than expected experienced onset under the age of 60 years and a lower than expected

proportion experienced onset over the age of 70. The sample therefore underrepresents those diagnosed after retirement age. Increasing age is known to be negatively associated with social participation (Dickens et al., 2011; Due et al., 1999; Bowling 1991) and therefore age may have influenced social network data relative to the population of people with PD. It should be noted, however, that support seeking characteristics of support group members may not reflect those of the wider population (Davison et al., 2000). Support seeking among members of a range of illness support groups was not correlated to either age or gender (Biegel et al., 2004) suggesting that the age profile of the sample may not have contributed substantially to social network and activity rates.

The sample was relatively narrowly concentrated in the middle of the socioeconomic range and had relatively high educational attainment compared with the general population. Therefore it is not representative of a large proportion of the population who are at the higher and lower ends of each scale. This may be an effect of the recruitment process as support group members are more likely to be middle class (Deanes et al., 1998; Biegel et al., 1994; Taylor et al., 1986). Having greater resources reduces the impact of certain barriers to accessing social opportunities such as providing transport and so the social class profile of the sample may have elevated some aspects of social activity where there is dependency on private transport. Higher social status is also associated with larger social networks (Ajrouch et al., 2005). Effects of education are more complex. People with lower educational attainment report

greater numbers of friends (Tijhuis et al., 1998) and also greater numbers of people they are close to (Ajrouch et al., 2005). It is therefore difficult to be certain of what effects if any the social and educational profile of the sample may have had on the study results. The sample did not include any participants from minority ethnic backgrounds. This was not planned. However, the exclusion criteria, which included a requirement for participants to be native speakers of English for purposes of data standardisation may have excluded potential volunteers from these communities. Recruitment from support groups may have reinforced this as there is some evidence that support group members are likely to be white (Taylor et al., 1986) although this finding may need to be revisited in the current time for groups which have been established in more ethnically diverse areas of the UK. The sample is therefore not representative of non-white ethnic groups. It is possible that social network and activity patterns differ in these groups but this study cannot report on that issue.

It might be thought that support group members are drawn from those who are more generally sociable anyway which predisposes them to having larger social networks and more social activity and that this will bias the results of the current study. Evidence from other studies of support group members does not confirm this. Membership of other groups is not related to support group membership (Biegel et al., 2004) and nor is friendliness (Davison et al., 2000). Motivations to join support groups are not primarily social but centre on opportunities to learn and be with people with a shared predicament and shared identity. Where conditions are socially embarrassing, as is often described by people with PD,

people may join because of difficulties with interpersonal relations in other social situations rather than because such relations are already a strength (Davison et al., 2000; Deans et al., 1998).

Some characteristics of the sample, therefore, may have influenced overall patterns of social networks and activity and the results should not be interpreted as generalizable to the population of all people with PD

8.5.5 Strengths

The research philosophy adopted was that of pragmatism, employing a mixed methods approach. Although requiring a deeper commitment to the investigation than a single method approach and challenging the researcher by posing a greater range of methodological and analytic challenges the mixed methods approach to the research question can be regarded as a strength of the research process. The combined approach provided opportunities to see beyond the aggregate group results, to understand better the heterogeneity of the sample, to understand the contributions that other aspects of PD were making to social change and to reveal some of the contextual factors which influenced social participation. It was evident from the complementarity of the two data sets that each was able to some degree to offset the limitations of the other.

A further strength of the research process was the use of sensitive statistical techniques to understand changes in quantifiable variable of social lives. The complexity of the relationships between the independent variable of speech

impairment and the dependent variables of social activity, network and anxiety were revealed using multivariate techniques including discriminant function analysis. It was evident from this analysis that social networks and social activities are fundamentally related and this lends weight to the argument above that an integrated data collection approach should be adopted in the future.

The measures of social activity and network, although having certain limitations as described above, benefited the research process through their flexible delivery format. It was possible to collect richer data by systematic extension of questioning of participants e.g. collecting data on different categories of relationship within the network.

Use of a measure of social anxiety with a group of speakers with an acquired communication impairment was novel. The sensitivity of the scale to detect differences in social anxiety related to specific social situations in this population indicates that there is potential to explore social anxiety in a range of communication impairments in which this dimension has so far been ignored.

8.6 Further Research

A first step in extending this research should be to document the social impact of dysarthria on more diverse group of participants. This should include those with more severe dysarthria and Parkinson's disease, but also where the dysarthria arises from other aetiologies, in order to understand the impact of dysarthria on the wider population of dysarthric speakers. Additionally, as dysarthria is commonly only one of a range of co-occurring impairments, a

study is needed which is large enough to use techniques such as multiple regression to identify the contributions of a wider range of factors to changes in social life in addition to speech. This would also address some of the limitations of the current study.

Discriminant function analysis pointed to the interrelationship of social variables which are influenced by speech impairment. It would be desirable to develop a measure of social functioning which integrates both social network and social activity data and captures the importance of relationships within that framework.

Although the research did not begin with the aim of describing the social capital of the participants, the dependent measures used were key indicators of structural social capital. This study therefore, provides a first, but incomplete, view of some aspects of the social capital of people with dysarthria. An area of research that should be explored further would include cognitive aspects of social capital. A more complete picture of social capital in speakers with dysarthria and other communication impairments would enable policy makers to quantify the additional health risks posed where social capital has been eroded. Such research might include measures of social trust and social cohesion such as that used by Rosenheck et al. (2001) and could adopt the multidimensional approach used by Coulthard, Walker, & Morgan (2002) which embraces not only the different components of social capital i.e. structural and cognitive, but also the different types of social capital i.e. bridging and bonding. There is a recognised need to identify methods of social capital formation as health

benefits have been shown to result from social interventions (Greaves and Farbus, 2006). Measuring social capital could help tackle health inequalities (Pilkington, 2002). There is therefore a role for SLTs in taking this approach with their client groups. Practical ways of enhancing social activity have been identified, such as the Connect organisation for people with aphasia (Connect, 2013), but wider health outcomes in relation to communication impaired populations have not.

9 Chapter 9 Conclusion

9.1 Summary of findings

Investigations of the impact of dysarthria on a sample of speakers with PD found that presence of dysarthria was associated with raised levels of social anxiety, particularly for social situations involving initiating contact with others. Severity of dysarthria was associated with reduction in social activity and social networks. Satisfaction with social activity was lower in both mild and moderately dysarthric speakers than in control participants. These group differences were observed despite large variance among individuals on social variables which indicated that in some speakers with dysarthria social activity and network levels were preserved at high levels.

Thematic analysis of accounts of social change largely confirm existing literature regarding presence and nature of impact of dysarthria on social participation and demonstrated the complex, multifactorial nature of change. In this sample there was more evidence of ways in which participants demonstrated resilience to change. Findings were aligned with a biopsychosocial model of health and illness. Emergent theoretical constructs modelled pressures on social change as being either ‘direct’ (impairment and activity centred) which were adverse in impact, or ‘indirect’ (contextual environmental and personal factors) which could be both beneficial and adverse in their impact on social participation. Discriminant function analysis identified dimensions of social change sensitive to motor speech impairment which were

related to structure and to social anxiety. Structural changes in social variables represent loss of social capital and may have negative consequences for health as well participation. Such structural social effects have been reported for other communication impairments but this study has demonstrated them in relation to motor speech impairment for the first time.

Social variables were generally not sensitive to variation in speech intelligibility but were sensitive to variation in motor speech impairment. This has implications for the understanding of what speakers perceive to be salient aspects of speech change with respect to impact on social behaviour. Levels of social activity and network may have been affected by sample characteristics. Speakers with dysarthria and PD were normally functioning in cognition, depression, anxiety and apathy unlike many people with PD in whom interactions between these variables and speech are likely to be seen. In addition, participants had relatively high levels of education and social status which are known to influence social variables. Findings from the current study must therefore be interpreted with caution in relation to the wider population of people with dysarthria and PD. Motor speech impairment may have a specific impact on participation but will typically do so as part of a complex pattern of impairments.

Findings from the current study add weight to Yorkston et al (2012)'s proposal that level as well as experience of participation should be recorded. Levels of social activity and network are susceptible to change where communication

impairment is present and as indicators of social capital it is important that these effects of communication change are understood both for purposes of planning clinical intervention and developing policy. These measures should be collected alongside psychosocial profiling such as the Dysarthria Impact Profile (Walshe et al., 2009) in order to fully understand the individual situation.

These findings show that dysarthria can be understood within the domain of social capital as well as within the domains of health and communication and this has both practical and theoretical implications. Where communication impairment impacts on social capital the consequences are of social as well as individual importance and may also be of importance to the broader health of the speaker. This perspective can inform intervention planning. A more detailed description of the nature and type of social capital held by those with dysarthria and other communication impairments might now be undertaken, for example exploring the balance of bridging and bonding capital and collecting data on aspects of networks including support and reciprocity.

9.2 The contribution to knowledge

This investigation has demonstrated for the first time that the impact of dysarthria on structural aspects of social participation (social activity and social network) occurs at a level that can be recorded quantitatively and which therefore permits comparison between and within groups of speakers with dysarthria. This is of value to clinicians who may use such insights when planning interventions which take account of the social as well as the communicative impact of speech impairment. This finding is also of relevance to

policy makers when considering the wider health consequences of changes to the social capital and social inclusion of people with speech, language and communication needs, especially where those needs co-occur with other disabilities.

A number of specific findings should be noted, acknowledging that this sample of participants is not representative of all speakers with dysarthria in Parkinson's disease. Global satisfaction with number of social activities is significantly impacted by the presence and severity of dysarthria and this is now supported by quantitative evidence of changes to social activity consequent on onset of dysarthria. The number of leisure social activities and the number of formally organised social activities is significantly affected by severity of dysarthria in Parkinson's disease and this effect is distinct from the impact of other aspects of the disease such as mobility. Social activity may be similarly affected in forms of dysarthria associated with other progressive degenerative diseases. In addition, size of social network is also significantly affected by dysarthria with a particular negative impact on specific categories of network member i.e. friends and relations outside the immediate family.

The findings indicate that negative impact on both activity and network is manifest when dysarthria reaches a threshold level of moderate severity, although there is considerable individual variation in social response to dysarthria. Some aspects of social functioning are preserved even where dysarthria is moderately severe and these are located especially around

immediate family relationships. Motor speech impairment is more closely related to extent of social changes than intelligibility and may therefore be a better indication of severity from the speaker rather than listener perspective.

Level of social anxiety associated with dysarthria has not previously been documented. Presence of dysarthria in Parkinson's disease is associated with significantly raised levels of social anxiety and this effect is independent of the severity of dysarthria. However, in most social situations social anxiety is not significantly different for dysarthric speakers. Social anxiety is particularly high in social situations which require speakers to initiate contact with another person but not in situations which involve self-expression, such as giving an opinion or a compliment. Social anxiety in dysarthria is therefore shown to be a significant contributor to changes in social functioning.

Accounts of participants show that the relationships between quantitative social variables can be mapped on to components of the ICF framework, validating this model for the interpretation of the impact of dysarthria on health and well-being.

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Appendix 1. Contact letter, Parkinson's UK support groups.

Dear

I am a speech and language therapist and senior lecturer at De Montfort University where I lecture in motor speech disorders such as that arising in Parkinson's disease. I am currently undertaking doctoral research into aspects of communication in Parkinson's disease. My main area of interest is in understanding more about the relationship between speech difficulties and the ways in which they affect the social participation of people with Parkinson's disease.

I would just like to ask if, in principle, members of your branch might be interested in supporting this work and whether you would permit me to come and speak about it to a branch meeting at some stage. I would be very happy to fit in with whatever time suited you. The aim would be to outline the purpose of the research and the nature of recordings and interviews that I would like to carry out. I am happy to discuss any questions that arise too.

Many thanks for your time. I look forward to hearing from you.

Yours sincerely,

Adam Brown
Senior Lecturer in Speech and Language Therapy
Faculty of Health and Life Sciences
De Montfort University
The Gateway
Leicester
LE1 9BH
0116 207 8809
abrown02@dmu.ac.uk

Appendix 2.Participant details Number

Date of birth Age at visit

Diagnosis of PD Yes No Type

Date of diagnosis

Medication

Date and type of first symptoms

Is speech affected Yes No

Date of first speech signs

SLT intervention for PD

Other Medical History

Other communication history Yes No

Occupation or previous occupation

Education: Secondary Further Graduate Post- grad

Home situation: living alone spouse/partner family: 1
2
3

First Language English yes no
Or number of years spoken

Appendix 3. Confirmation of ethical approval

Tuesday 2nd October 2007

Adam Brown
Health and Life Sciences

Dear Adam,

Re: Ethics application – Linguistic and social aspects of communication in Parkinson's disease (MPhil/PhD) (ref: 261)

I am writing regarding your application for ethical approval for a research project titled to the above project. This project has been reviewed in accordance with the Operational Procedures for De Montfort University Faculty of Health and Life Sciences Research Ethics Committee. These procedures are available from the Faculty Research and Commercial Office upon your request.

I am pleased to inform you that ethical approval has been granted by Chair's Action for your application. This will be reported at the next Faculty Research Committee, which is being held on 23rd October 2007.

Should there be any amendments to the research methods or persons involved with this project you must notify the Chair of the Faculty Research Ethics Committee immediately in writing. Serious or adverse events related to the conduct of the study need to be reported immediately to your Supervisor and the Chair of this Committee. Also, The Faculty Research Ethics Committee should be notified by e-mail to [redacted] when your research project has been completed.

Yours sincerely,

Professor Paul Whiting
Chair
Faculty of Health and Life Sciences
Research Ethics Committee

Appendix 4 Information for participants with Parkinson's disease.

Title: Linguistic and Social Aspects of Communication in Parkinson's Disease
Date:
Researcher: Adam Brown, Senior Lecturer, Speech and Language Therapy,
De Montfort University, Leicester, 0116 207 8809
abrown02@dmu.ac.uk

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 done and what it will involve.
Please take time to read the following information carefully. Talk to others about the study if you wish. Please ask if there is anything that is not clear or if you would like more information.

What is the purpose of the study? The purpose of this project is to investigate how difficulties with speech may affect the social lives of people with Parkinson's disease. By taking part you may help us to develop better ways of assessing communication in Parkinson's disease.

Who is involved in the study? The main researcher and the project supervisors are all from De Montfort University in Leicester and are involved in teaching speech and language therapy and psychology students.

Do I have to take part? No. It is entirely 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. A decision to withdraw at any time, or a decision not to take part, will not affect any service you receive.

What will happen to me if I take part? I will visit you in your home or at another place if you prefer on two occasions. I will record you speaking, assess movements of your lips, tongue and other things which are part of producing speech. I will ask you to complete some questionnaires, discuss with you your social activity and collect some information about the history of your Parkinson's disease.

Each visit will take around one hour. I will arrange the date and time to suit you and to fit in with your medication cycle.
Visit 1: record speech, assess speech movements, collect information about your medical condition
Visit 2: questionnaires, discuss social activity and interview about experiences

What do I have to do? If you participate you have to agree to be recorded and to answer the questions asked.

You are encouraged to ask any questions at any time about the nature of the study and the methods that I am using. Your suggestions and concerns are important to me; please contact me at any time at the address/phone number listed above.

Will my taking part in the study be kept confidential? Yes. All the information about your participation in this study will be kept confidential.

I guarantee that the following conditions will be met:

- Your real name will not be used anywhere in the project or in the written report so it will not be possible to identify you;
- The information you provide will only be seen by the researchers and no-one else.
- Any recordings will not be heard by anyone except the researchers and will have codes on not names to safeguard confidentiality.
- All the recordings will be erased at the end of the study.
- All the questionnaires will be shredded at the end of the study
- All the information will be kept in securely locked storage throughout the project.
- If you decide to withdraw at any stage, any information that has been collected will be destroyed or returned to you if you prefer.

What are the possible disadvantages and risks of taking part? <u>You will not be asked to do anything harmful</u>. However, if you do not wish to answer any questions you may refuse to do so. If for any reason you are not comfortable during a visit you may end it immediately. If you need to discuss any concerns that you have about your speech I may be able to provide advice. It is important to understand that you will not receive any speech therapy as part of the project.

What if there is a problem? *Any complaint about the way you have been dealt with during the study or any possible discomfort you might experience will be addressed.* If you wish to complain for any reason then please contact the research supervisor at the address/number at the bottom of the sheet.
In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have legal grounds for compensation from De Montfort University (who have indemnity for

negligent harm), but you may have to pay your legal costs. I emphasise that you will not be asked to do anything harmful.

What will happen to the results of the research study? From this information, I will write a report about all the participants in the project. The results may be published but no-one will be identified. A summary of the results will be given to you if you wish. I will arrange to talk about the results at a Parkinson's Disease Society branch meeting.

.

Who has reviewed the study? The study has been approved by the Research Ethics Committee of the Faculty of Health and Life Sciences at De Montfort University, Leicester.

Research Supervisor

Mr D. Rowley
Principal Lecturer, School of Allied Health Sciences, De Montfort University
Leicester 0116 257 7766 dtr@dmu.ac.uk

Appendix 5 Information for control participants.

Title: **Linguistic and Social Aspects of Communication in Parkinson's Disease**

Date:

Researcher: Adam Brown, Senior Lecturer, Speech and Language Therapy, De Montfort University, Leicester, 0116 207 8809
abrown02@dmu.ac.uk

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 done and what it will involve.
Please take time to read the following information carefully. Talk to others about the study if you wish. Please ask if there is anything that is not clear or if you would like more information.

What is the purpose of the study? The purpose of this project is to investigate how difficulties with speech may affect the social lives of people with Parkinson's disease. By taking part you may help us to develop better ways of assessing communication in Parkinson's disease.

Why have I been approached? I need to compare the communication of people with Parkinson's disease with people who do not have a communication problem.

Who is involved in the study? The main researcher and the project supervisors are all from De Montfort University in Leicester and are involved in teaching speech and language therapy and psychology students.

Do I have to take part? No. It is entirely 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. A decision to withdraw at any time, or a decision not to take part, will not affect any service you receive.

What will happen to me if I take part? I will visit you in your home or at another place. I will record you speaking and I will ask you to complete some questionnaires, discuss with you your social activity and collect some information about your medical history.

The visit will take around 90 minutes. I will arrange the date and time to suit you.

What do I have to do? If you participate you have to agree to be recorded and to answer the questions asked.

You are encouraged to ask any questions at any time about the nature of the study and the methods that I am using. Your suggestions and concerns are important to me; please contact me at any time at the address/phone number listed above.

Will my taking part in the study be kept confidential? Yes. All the information about your participation in this study will be kept confidential.

- I guarantee that the following conditions will be met:
- Your real name will not be used anywhere in the project or in the written report so it will not be possible to identify you;
- The information you provide will only be seen by the researchers and no-one else.
- Any recordings will not be heard by anyone except the researchers and will have codes on not names to safeguard confidentiality.
- All the recordings will be erased at the end of the study.
- All the questionnaires will be shredded at the end of the study
- All the information will be kept in securely locked storage throughout the project.
- If you decide to withdraw at any stage, any information that has been collected will be destroyed or returned to you if you prefer.

What are the possible disadvantages and risks of taking part? You will not be asked to do anything harmful. However, if you do not wish to answer any questions you may refuse to do so. If for any reason you are not comfortable during a visit you may end it immediately. If you need to discuss any concerns that you have about your speech I may be able to provide advice.

What if there is a problem? *Any complaint about the way you have been dealt with during the study or any possible discomfort you might experience will be addressed.* If you wish to complain for any reason then please contact the research supervisor at the address/number at the bottom of the sheet.
In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have legal grounds for compensation from De Montfort University (who have indemnity for negligent harm), but you may have to pay your legal costs.

What will happen to the results of the research study? From this information, I will write a report about all the participants in the project. The

results may be published but no-one will be identified. A summary of the results will be given to you if you wish
.

Who has reviewed the study? The study has been approved by the Research Ethics Committee of the Faculty of Health and Life Sciences at De Montfort University, Leicester.

Research Supervisor

Mr D. Rowley
Principal Lecturer, School of Allied Health Sciences, De Montfort University
Leicester 0116 257 7766 dtr@dmu.ac.uk

Appendix 6 Consent form.

CONSENT FORM

Title of Project: Linguistic and Social Aspects of Communication in Parkinson's Disease

Name of Researcher: Adam Brown

Please initial box

1. I confirm that I have read and understand the information sheet dated 10/01/08 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without any care being affected ☐
3. I understand that I will be asked to make audio and video recordings of my speech and answer questions. I give consent for the information gathered to be analysed ☐
4. I understand that the results may be published but that confidentiality will be maintained throughout and I will not be referred to by name or any identifying information ☐
5. I agree to take part in the above study ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

When completed, 1 for participant; 1 for researcher file

Appendix 7 Letter to participants

Dear

Research into Communication in Parkinson's Disease

I am a speech and language therapist and senior lecturer at De Montfort University in Leicester where I lecture in speech disorders such as those arising in Parkinson's disease. I am currently undertaking research into aspects of communication in Parkinson's disease. My main area of interest is in understanding more about the relationship between speech difficulties and the ways in which they affect the social activity of people with Parkinson's disease with a long term view to improving the way in which speech and language therapists work with people with Parkinson's disease.

I enclose an information sheet about the research that I am doing.

Please could you read the information and then, if you would like to take part in the research, complete the consent form and return it to me in the enclosed stamped addressed envelope. There is a spare copy of this form for you to keep on file.

Feel free to contact me if there is anything you wish to discuss.
Thank you for your time.

Yours sincerely

Adam Brown
Senior Lecturer
Speech and Language Therapy
De Montfort University
0116 207 8809
abrown02@dmu.ac.uk

encl.
Outline of project
Information for participants
Consent form x2

Outline of Project

BACKGROUND
The research idea has come from my awareness that in other areas of communication a lot has been done to understand the impact of communication difficulties on the social lives of people who have them. However, for people with motor speech difficulties very little has been done so far.

AIM
The general aim is to examine the speech characteristics of people with Parkinson's disease to see if they can be used to predict limitations on social activity.

OUTCOME
This may help us to design better assessments and to plan therapy more effectively.

PROCEDURE
I will need to make recordings of people speaking which will involve some reading aloud and some spontaneous conversation. Participants will also need to complete some questionnaires which I can use to find out about social activity.
In addition I will need to carry out assessments which are typically used by speech and language therapists to assess speech.

I am happy to visit people in their homes if they prefer.

I will provide a summary of the results for all the participants at the end of the project.

At present I am at an early stage of the project and expect to be able to start visiting people and making recordings in January 2008

Appendix 8 Lille Apathy Rating Scale

- Instructions for administration of the Lille Apathy Rating Scale –

The Lille Apathy Rating Scale (LARS) comprises 33 queries belonging to nine domains, each corresponding to a clinical manifestation of apathy.
The interview is structured and the questions should to be posed exactly as stated. To obtain the best validity, it is not advisable to change the vocabulary or to add additional comments to the questions.
Before beginning the interview, the patient has to be informed as follows:
"I am going to ask you some questions about your daily life. It is important that you base your answers on your life over the last four weeks"
If the patient mentions personal events or any time previous the last month, he or she must be reminded that only the current situation must be referred to: *"Please try to answer according to your current way of life, by referring to the last four weeks"*
A precise scoring mode is proposed for each reply and should be followed as closely as possible. When an item does not apply to the patient, it is scored "0", for non-applicable (NA). When the reply is not clear at all and cannot be elucidated, it is also scored "0" for a non-classifiable reply.
The patient overall score ranges from –36 to +36

- Lille Apathy Rating Scale –

1. Everyday productivity

- What do you do during the day? Tell me about your day-to-day life.

Does she/he ready[1]

yes easily	0
only after prompting	-1
spontaneous reply but only after three times	-2
Immediate reply, one activity mentioned without hesitation	-1
Immediate reply, several activities mentioned without hesitation	-3

Number and variety of activities mentioned

none	2
one activity but prompting needed to obtain another	-1
several activities mentioned	0
detailed organization of a typical day but every day follows the same schedule	-1
detailed organization of a typical day but the reply shows that the activities change according to the day of the week or the time of year (for example housework, going to the cinema, watching TV, gardening, visiting friends, etc.)	-2

2. Interests

- What are you interested in? What do you like doing to keep yourself occupied?

[1] The delay might reflect a deficit in or absence of reactivity from the subject. Delays due to speaking or word-finding difficulties should not be considered when scoring these items

Time taken to reply

no reply	2
reply after prompting	1
spontaneous reply but only after some time	0
[illegible]	-1
[illegible]	-2

Number of activities mentioned

none or only one	1
several	0
regrets having to choose between so many activities	-1

- How many times a week do you ...*(do the first hobby or pastime mentioned above)*?

Less than once a week	1
Once or several times a week	0
Regrets not being able to devote more time to the activity	-1

3. Taking the initiative

- In general, do you decide to do things on days when someone have to push you a little?

I have to be pushed	1
N.A. ☐ Non-classifiable reply ☐	0
I decide to do things myself	-1

- When you have to go to an appointment, a meeting or a formal occasion, do you have to be told to get yourself ready?

I need to be told	1
N.A. ☐ Non-classifiable reply ☐	0
I get ready spontaneously	-1

- When you have to make an appointment (for example with the doctor or dentist), do you do it yourself or do you wait for someone to do it for you?

I wait for someone to do it for me	1
N.A. ☐ Non-classifiable reply ☐	0
I do it myself	-1

- Do you take part spontaneously in daily living activities or do you need to be asked?

I have to be asked	1
N.A. ☐ Non-classifiable reply ☐	0
I take part spontaneously	-1

4. Novelty seeking

- Do you like finding out about something new (a new TV programme or a new book)?

No, that doesn't interest me	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, that interests me	-1

- Do you like trying out new products, tools or recipes that you're not familiar with?

No, that doesn't interest me	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I like trying things I'm not familiar with	-1

- Do you like visiting places you've never been to before?

No, that doesn't interest me	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I like visiting places I've never been to before	-1

When you go out for a drive or when you're travelling by train or bus, do you enjoy looking at the countryside, the houses?

No, that doesn't interest me	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I like to see if anything has changed	-1

5. Motivation - Voluntary actions

When you decide to do something, are you easily able to make an effort or is it difficult?

I find it difficult to make an effort	1
N.A. ☐ Non-classifiable reply ☐	0
I can easily make an effort	-1

When you don't manage to do something, do you try to find other solutions?

No, I give up	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I try again	-1

When you decide to do something, do you see it through to the end or do you tend to give up?

I tend to give up (I am easily discouraged)	1
N.A. ☐ Non-classifiable reply ☐	0
I see it through to the end	-1

When you can't find something (for example a document or an object), do you go to a lot of trouble looking for it?

No, if I don't find it quickly, I stop looking	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I keep looking until I find it	-1

6. Emotional responses

When you watch a film, do you easily become emotional or moved?

No, I don't experience any particular emotion	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I am easily moved	-1

When someone tells you a joke or when you watch a comedy sketch on TV, do you laugh easily?

No, I don't experience any particular emotion	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, it makes me laugh	-1

Do you feel happy when you hear some good news?

No, I don't experience any particular emotion	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I'm happy	-1

Do you feel sad when you hear some bad news?

No, I don't experience any particular emotion	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I'm sad, it worries me	-1

7. Concern

- When you have a problem (for example when your TV set breaks down), does it worry you?

Yes,	1
N.A. Non-classifiable reply	0
Yes, I worry easily	-1

- When something's not working or when something unexpected happens, do you think about finding a solution?

No, I give up	1
N.A. Non-classifiable reply	0
Yes, I look for a solution	-1

- When your parents or children have a minor problem (when they're ill, for example), does that concern you, do you worry about them?

No, I don't feel very concerned about that	1
N.A. Non-classifiable reply	0
Yes, I worry.	-1

- Do you like to ask how your family and friends are on a regular basis?

No, often I wait until someone tells me how they are	1
N.A. Non-classifiable reply	0
Yes, I often ask them how they are (I phone them, etc).	-1

8. Social life

- Do you have friends?

Yes, real friends (I don't see them very often)	1
N.A. Non-classifiable reply	0
Yes, real friends (I meet or see a lot of)	-1

- When you meet friends, do you enjoy spending time with them or is it a chore?

It's a chore	1
N.A. Non-classifiable reply	0
I enjoy it	-1

- In conversation, do you start talking or do the others tend to speak to you first?

I only talk if someone starts talking to me	1
N.A. Non-classifiable reply	0
I start talking with no problem	-1

- During a discussion, do you give your own opinion spontaneously or do you fall into line with someone else's opinion?

I tend to fall into line with someone else's opinion	1
N.A. Non-classifiable reply	0
I give my own opinion spontaneously	-1

9. Self-awareness

. When you've finished doing something, do you take stock of the situation and think about what is going well and what's not?

No, I don't think about the end result	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I take stock of the situation.	+1

. After having taken a decision, do you sometimes think that you've made the wrong choice?

No, I'm happy with the choice I make	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I sometimes regret having made certain choices	-1

. When you've been unpleasant to someone, do you sometimes feel guilty afterwards?

No, I don't care	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I'm ashamed of myself	+1

. If, during a discussion, your position about something in the evening, are you able to admit it - at least to yourself?

No, I don't admit that I'm in the wrong	1
N.A. ☐ Non-classifiable reply ☐	0
Yes, I admit it.	+1

Total score	/36

Sub-scales		Scores
Everyday proactivity	EP	-4 -3 -2 -1 0 1 2 3 4
Interests	INT	-4 -3 -2 -1 0 1 2 3 4
Taking the initiative	INT	-4 -3 -2 -1 0 1 2 3 4
Planning meetings	NS	-4 -3 -2 -1 0 1 2 3 4
Mood swings - Voluntary control	M	-4 -3 -2 -1 0 1 2 3 4
Emotional compliance	EC	-4 -3 -2 -1 0 1 2 3 4
Concern	C	-4 -3 -2 -1 0 1 2 3 4
Social life	SL	-4 -3 -2 -1 0 1 2 3 4
Self-confidence	SA	-4 -3 -2 -1 0 1 2 3 4

Factorial sub-scores are calculated from sub-scale scores using the formulas given below.

Factorial sub-scores			Scores
Intellectual curiosity	(INT+NS+M+SL)/4	IC	-4 -3 -2 -1 0 1 2 3 4
Emotion	(ER+C)/2	E	-4 -3 -2 -1 0 1 2 3 4
Action initiation	(EP+INT)/2	AI	-4 -3 -2 -1 0 1 2 3 4
Self-awareness	(SA)	SA	-4 -3 -2 -1 0 1 2 3 4

Appendix 9 The Short Portable Mental Status Questionnaire

THE SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE (SPMSQ)

		Response	Incorrect responses
1	What is today's date? (date, month and year)		
2	What is the day of the week today?		
3	What is the name of this place?		
4	What is your phone number? What is your street address? (ask only if has no telephone)		
5	How old are you?		
6	When were you born?		
7	Who is the current prime minister?		
8	Who was the prime minister before him?		
9	What was your mother's maiden name?		
10	Can you count backward from twenty in threes?		

Education: Left school at 14 ❒
Left school 15-18 ❒
Beyond 18 ❒

SCORING:

0-2 errors: normal mental functioning,
3-4 errors: mild cognitive impairment
5-7 errors: moderate cognitive impairment
8 or more errors: severe cognitive impairment

Subtract 1 if subject has had any higher education

Add 1 if subject left school at 14

Appendix 10 The Parkinson's Disease Activities of Daily Living Scale

The Parkinson's Disease Activities of Daily Living Scale

Please tick one of the descriptions that best describes how your Parkinson's disease has affected your day-to-day activities in the last month

1) No difficulties with day-to-day activities. ❒
For example: Your Parkinson's disease at present is not affecting your daily living.

2) Mild difficulties with day-to-day activities ❒
For example: Slowness with some aspects of housework, gardening or shopping. Able to dress and manage personal hygiene completely but rte is slower. You may feel that your medication is not quite as effective as it was.

3) Moderate difficulties with day-to-day activities ❒
For example: Your Parkinson's disease is interfering with your daily activities. It is increasingly difficult to do simple activities without some help such as rising from a chair, washing, dressing, shopping, housework. You may have some difficulties walking and may require assistance. Difficulties with recreational activities or the ability to drive a car. The medication is now less effective.

4) High levels of difficulty with day-to-day activities ❒
For example: you now require much more assistance with activities of daily living such as washing, dressing, housework or feeding yourself. You may have greater difficulties with mobility and find you are becoming more dependent for assistance from others or aids and appliances. Your medication appears to be significantly less effective.

5) Extreme difficulties with day-to-day activities ❒
For example: you require assistance in all daily activities. These may include dressing, washing, feeding yourself or walking unaided. You may now be housebound and obtain little or no benefit from your medication.

Appendix 11 The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale
Zigmond, A.S and Snaith R.P. (1983)

1.
I feel tense or wound up

Most of the time	3
A lot of the time	2
From time to time	1
Not at all	0

2.
I still enjoy the things I used to enjoy

Definitely as much	0
Not quite so much	1
Only a little	2
Hardly at all	3

3.
I get a sort of frightened feeling as if something awful is about to happen

Very definitely and quite badly	3
Yes, but not too badly	2
A little but it doesn't worry me	1
Not at all	0

4.
I can laugh and see the funny side of things

As much as I always could	0
Not quite as much now	1
Definitely not so much now	2
Not at all	3

5.
Worrying thoughts go through my mind

A great deal of the time	3
A lot of the time	2
From time to time but not too often	1
Only occasionally	0

6.
I feel cheerful

Not at all	3
Not often	2
Sometimes	1
Most of the time	0

7.
I can sit at ease and feel relaxed

Definitely	0
Usually	1
Not often	2
Not at all	3

8.
I feel as if I am slowed down

Nearly all the time	3
Very often	2
Sometimes	1
Not at all	0

9.
I get sort of frightened like butterflies in the stomach

Not at all	0
Occasionally	1
Quite often	2
Very often	3

10.
I have lost interest in my appearance

Definitely	3
I don't take so much care as I should	2
I may not take quite as much care	1
I take just as much care as ever	0

11.
I feel restless as if I have to be on the move

Very much indeed	3
Quite a lot	2
Not very much	1
Not at all	0

12.
I look forward with enjoyment to things

As much as I ever did	0
Rather less than I used to	1
Definitely less than I used to	2
Hardly at all	3

13.
I get a sudden feeling of panic

Very often indeed	3
Quite often	2
Not very often	1
Not at all	0

14.
I can enjoy a good book or radio or TV programme

Often	0
Sometimes	1
Not often	2
Very seldom	3

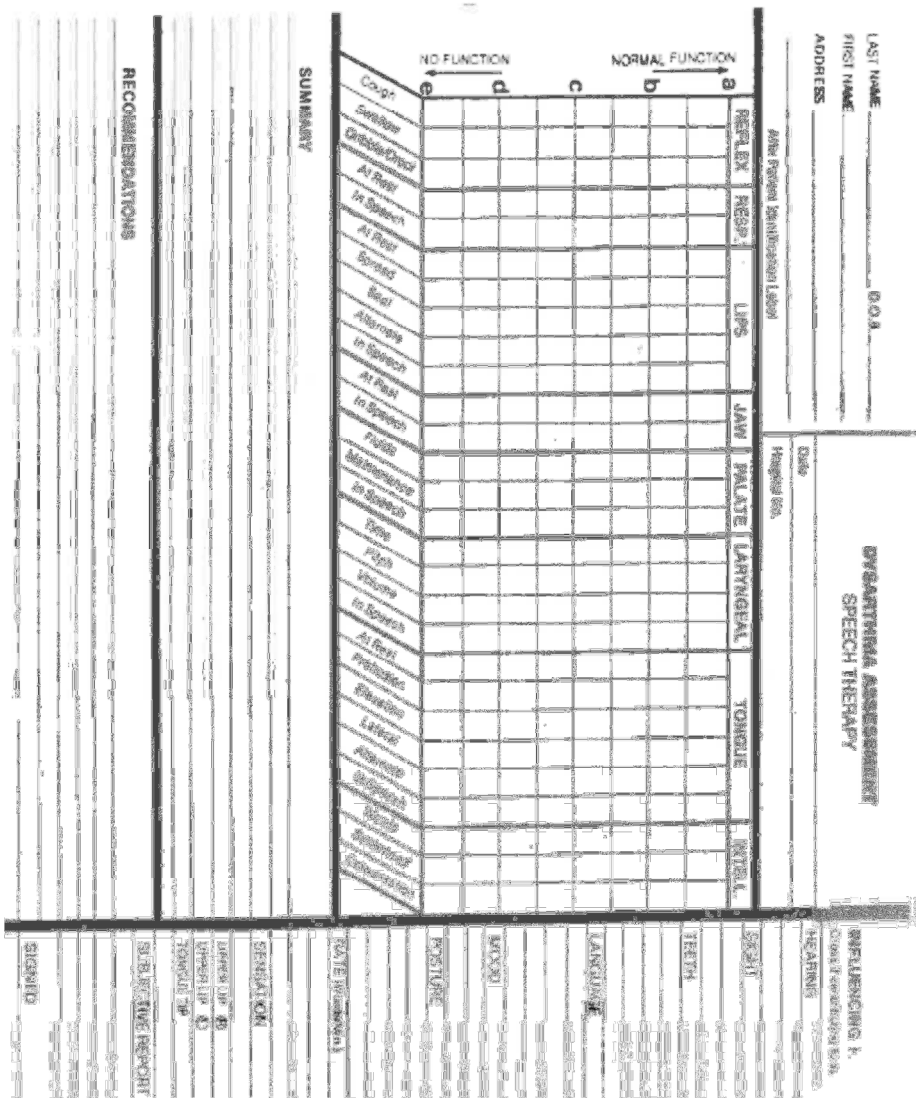
Odd numbered items = anxiety sub-scale
Even-numbered items = depression sub-scale

Total Anxiety /21

Total Depression /21

Normal	0-7
Mild	8-10
Moderate	11-15
Severe	16-21

Appendix 12 The Frenchay Dysarthria Assessment



Appendix 13 The Social Activities Checklist

Social Activities Checklist (SOCAT: Cruice, 2001)

Please tick to indicate how often you do each activity and write in with whom you usually do the activity (e.g. by self, spouse, children, relatives, friends, colleagues)

		Weekly	Fort - nightly	Monthly	Rarely	Not at all	n/a
1	Visit exhibitions, museums, libraries						
2	Go to the movies, theatres, concerts, plays						
3	Go to restaurants						
4	Go shopping						
5	Watch television						
6	Read						
7	Exercise or play sports						
8	Take part in outdoor activities						
9	Travel or go on tours						

10	Play cards or indoor games						
11	Work on hobbies						
12	Play with or help children/grandchildren						
13	Visit or help friends/relatives						
14	Go to family festivities or parties						
15	Go to church events or religious communities events						
16	Go to meetings of community voluntary organisations or charitable societies						
17	Go to professional events or union meetings						
18	Go to classes or lectures						
19	Go to clubs						
20	Go to political activities or occasions						

Please tick one

I am satisfied with the activities I do	
I would like to be doing more activities	
I would like to be doing fewer activities	

Is there anything which limits you in doing these activities? Please write any comments you have here.

Appendix 14 The Convoy Model of Social Network Analysis

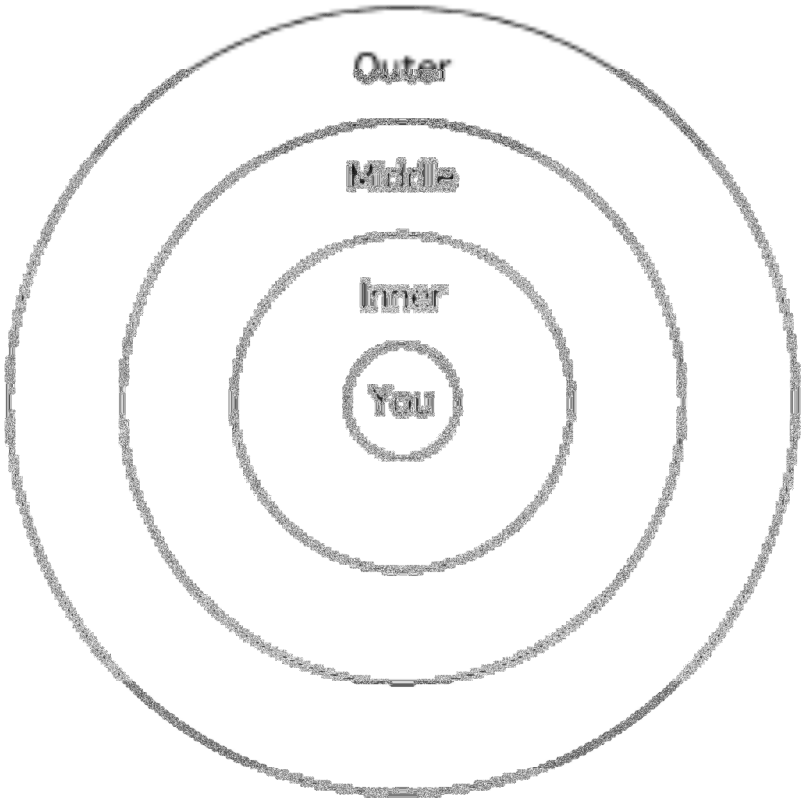
Social Network Analysis (Antonucci & Akiyama, 1987)

In this diagram you write the first names of people who are important in your life right now. The three circles separate out people on the basis of how important or
how close they are to you. Close in terms of relationship, not close in terms of geographical distance.

In the inner circle, you write the first names of people to whom you feel so close that it is hard to imagine life without them.

In the middle circle, you write the first names of people whom you may not feel that close but are still very important to you.

In the outer circle, you write the first names of people whom you haven't mentioned already but who are close enough and important enough in your life that they should be placed in your personal network


Outer
Middle
Inner
You

Appendix 15 Inventory of Interpersonal Situations (IIS)

Van Dam-Baggen and Kraaimaat (2000)

Instruction for Part 1: Discomfort

This inventory consists of a number of interpersonal situations. Please indicate the degree of DISCOMFORT you would experience in each of these situations.

Use the following answer key:

1. no discomfort
2. a little discomfort
3. a fair amount of discomfort
4. much discomfort
5. very much discomfort

For example: If you feel a FAIR amount of discomfort when you join a conversation of a small group of people, then circle figure 3 as follows:

Joining a conversation of a small group of people 1 2 (3) 4 5

Please complete the following inventory. Take your time when you work from one situation to the next. There are no right or wrong answers; it is rather your opinion that matters.

Instruction for Part 2: Frequency Of Occurrence
In this part you will find the same 35 interpersonal situations as described in Part 1. This time you are to indicate HOW OFTEN you behave as described in the situations. Use the following answers:

1. I never do
2. I seldom do
3. I sometimes do
4. I often do
5. I always do

For example: If you NEVER are joining a conversation of a small group of people, you circle number 1 as follows:

Joining a conversation of a small group of people (1) 2 3 4 5

One by one you complete the list of interpersonal situations, taking your time. Again there are no right or wrong answers; it only matters what you think you do. Take your time to complete Part 2.

Items of the IIS

1. Joining a conversation of a small group of people.
2. Telling a friend that he/she is doing something that bothers you.
3. Resisting pressure to accept an offer (for example at the door, in the street).
4. Accepting a compliment for something you did.
5. Asking a friend to help you with something.
6. Requesting the return of something you have lent to someone.
7. Turning down a request to lend someone money.
8. Refusing a request from an authority figure (e.g., employer, superior, teacher).
9. Telling someone that you are pleased with what he/she did for you.
10. Asking someone to stop bothering you in a public place (theatre, subway).
11. Keeping eye contact during a conversation.
12. Asking for information (at a window or booth).
13. Initiating a conversation with an attractive male or female.
14. Expressing an opinion that differs from that of the person with whom you are talking.
15. Initiating a conversation with a stranger.
16. Expressing an opinion that differs from that of those around you.
17. Complimenting someone for a job well done.
18. Returning a defective item (for example, in a store or restaurant).
19. Asking for a further explanation about something you did not understand.
20. Expressing your opinion in a conversation with a group of unfamiliar people.
21. Telling someone that he/she offended you.
22. Refusing a request from a person you like.
23. Expressing your appreciation for a present.
24. Telling someone that he/she is good looking.
25. Discussing why someone seems to avoid you.
26. Telling someone that you like it that he or she appreciates you.
27. Agreeing with a compliment about your looks.
28. Telling someone that you are pleased with something you did.
29. Introducing yourself to someone.
30. Expressing your opinion of life.
31. Telling someone you no longer want to see him/her.
32. Insisting that someone contributes his/her share.
33. Telling someone that the way he/she is talking disturbs you.
34. Expressing your opinion to an authority figure (e.g., employer, superior, teacher).
35. Asking a friend to go out with you.

Please check if you marked all situations

Appendix 16 Tests of normal distribution of data.

One-Sample Kolmogorov-Smirnov Tests by Group
CONTROL
GROUP

	Age	Cognition Scale	Apathy Scale	Anxiety Scale	Depression Scale	Mobility Scale	SOCAT Total
N	30	30	30	30	30	30	30
Mean	70.90	9.67	-28.77	4.77	2.20	1.07	18.43
Std. Deviation	9.521	.606	2.909	2.712	1.562	.254	4.191
Kolmogorov-Smirnov Z	.661	2.421	.758	.781	1.192	2.941	.773
Asymp. Sig. (2-tailed)	.775	.000	.613	.575	.117	.000	.588

	SOCAT Leisure	SOCAT Informal	SOCAT Formal	SOCAT Cumulative	Network Total	Inner Circle Total	Middle Circle Total
N	30	30	30	30	30	30	30
Mean	12.27	3.93	2.20	54.77	28.07	8.47	9.40
Std. Deviation	2.227	1.946	1.584	15.007	13.575	4.501	6.886
Kolmogorov-Smirnov Z	1.174	1.021	1.188	.804	1.345	.956	.775
Asymp. Sig. (2-tailed)	.127	.249	.119	.537	.054	.320	.586

	Outer Circle Total	All close family	All other relatives	All friends	All other contacts	Interpersonal Discomfort	Interpersonal Frequency
N	30	30	30	30	30	30	30
Mean	10.20	3.63	5.47	13.90	5.63	63.40	106.00
Std. Deviation	10.087	2.512	4.812	11.397	7.369	15.151	14.858
Kolmogorov-Smirnov Z	1.537	1.058	1.219	.885	1.218	.807	.574
Asymp. Sig. (2-tailed)	.018	.213	.102	.414	.103	.532	.896

	IISD criticism	IISD opinion	IISD compliment	IISD initiate contact	IISD positive self statement	IISF criticism	IISF opinion
N	30	30	30	30	30	30	30
Mean	2.5133	1.9200	1.3200	1.4067	1.7767	2.2433	2.7233
Std. Deviation	.76372	.58804	.35467	.32049	.51104	.53219	.56182
Kolmogorov-Smirnov Z	.506	.799	1.273	.901	.923	.827	.822
Asymp. Sig. (2-tailed)	.960	.546	.078	.392	.362	.502	.509

	IISF compliment	IISF initiate contact	IISF positive self statement
N	30	30	30
Mean	3.7933	3.3167	3.2033
Std.	.56686	.52986	.46050

Deviation			
Kolmogorov-Smirnov Z	.895	.687	.851
Asymp. Sig. (2-tailed)	.399	.733	.463

ALL PD PARTICIPANTS

One-Sample Kolmogorov-Smirnov Test

	Age	Duration PD Months	Duration speech signs Months	Cognition Scale	Apathy Scale	Anxiety Scale	Depression Scale
N	43	43	43	43	43	43	43
Mean	69.05	108.77	61.88	9.33	-26.74	6.88	4.23
Std. Deviation	8.864	61.764	59.570	.808	3.639	3.893	1.850
Kolmogorov-Smirnov Z	.682	.793	1.483	2.030	.809	.684	.862
Asymp. Sig. (2-tailed)	.741	.556	.025	.001	.529	.737	.448

	Mobility Scale	Sentence Intelligibility	FDA Overall	SOCAT Total	SOCAT Leisure	SOCAT Informal	SOCAT Formal
N	43	43	43	43	43	43	43
Mean	2.51	91.851	7.1391	17.16	10.81	4.33	1.88
Std. Deviation	.703	12.8627	.94193	4.498	2.762	1.459	1.499
Kolmogorov-Smirnov Z	2.130	1.815	.911	.970	1.122	1.327	1.228
Asymp. Sig. (2-tailed)	.000	.003	.377	.303	.161	.059	.098

	SOCAT Cumulative	Network Total	Inner Circle Total	Middle Circle Total	Outer Circle Total	All close family	All other relatives
N	43	43	43	43	43	43	43
Mean	51.53	27.30	9.05	9.40	11.33	4.12	7.07
Std. Deviation	15.594	13.019	6.900	6.591	7.764	1.562	6.053
Kolmogorov-Smirnov Z	1.008	1.109	1.393	.996	1.253	1.491	1.451
Asymp. Sig. (2-tailed)	.262	.171	.041	.275	.086	.023	.030

	All friends	All other contacts	Interpersonal Discomfort	Interpersonal Frequency	IISD criticism	IISD opinion	IISD compliment
N	43	43	43	43	43	43	43
Mean	14.26	4.70	72.91	99.09	2.5884	2.2256	1.4186
Std. Deviation	9.851	6.239	23.446	17.894	.85446	.85915	.38251
Kolmogorov-Smirnov Z	.921	1.480	.772	.768	.512	1.372	1.576
Asymp. Sig. (2-tailed)	.365	.025	.590	.596	.956	.046	.014

	IISD initiate contact	IISD positive self statement	IISF criticism	IISF opinion	IISF compliment	IISF initiate contact	IISF positive self statement

N	43	43	43	43	43	43	43
Mean	1.9116	1.9512	2.2721	2.7791	3.5605	2.9581	2.9419
Std. Deviation	.75094	.68500	.53020	.57220	.74134	.70550	.62611
Kolmogorov-Smirnov Z	.989	1.167	.925	.775	.907	.845	1.100
Asymp. Sig. (2-tailed)	.282	.131	.359	.584	.383	.472	.178

MILD (INTELLIGIBILITY)

One-Sample Kolmogorov-Smirnov Test

	Age	Duration PD Months	Duration speech signs Months	Cognition Scale	Apathy Scale	Anxiety Scale	Depression Scale
N	22	22	22	22	22	22	22
Mean	69.18	95.45	64.73	9.55	-27.09	6.86	3.73
Std. Deviation	8.980	67.969	68.864	.596	3.308	3.895	1.751
Kolmogorov-Smirnov Z	.464	1.060	1.185	1.727	.606	.835	.717
Asymp. Sig. (2-tailed)	.983	.212	.121	.005	.856	.489	.683

	Mobility Scale	Sentence Intelligibility	FDA Overall	SOCAT Total	SOCAT Leisure	SOCAT Informal	SOCAT Formal
N	22	22	22	22	22	22	22
Mean	2.41	97.945	7.3009	17.82	11.23	4.68	1.68
Std. Deviation	.666	1.1915	1.00108	4.837	3.070	1.555	1.393
Kolmogorov-Smirnov Z	1.934	.765	.727	1.040	1.026	.593	.746
Asymp. Sig. (2-tailed)	.001	.602	.666	.230	.243	.873	.634

	SOCAT Cumulative	Network Total	Inner Circle Total	Middle Circle Total	Outer Circle Total	All close family	All other relatives
N	22	22	22	22	22	22	22
Mean	55.86	29.41	8.91	10.41	12.45	4.23	7.91
Std. Deviation	15.490	14.016	4.720	7.781	8.623	1.343	5.218
Kolmogorov-Smirnov Z	.929	.935	.817	.924	.954	.742	.670
Asymp. Sig. (2-tailed)	.354	.346	.517	.360	.323	.641	.761

	All friends	All other contacts	Interpersonal Discomfort	Interpersonal Frequency	IISD criticism	IISD opinion	IISD compliment
N	22	22	22	22	22	22	22
Mean	16.27	3.23	72.95	103.86	2.5500	2.1909	1.4727
Std. Deviation	11.829	4.587	23.190	17.164	.78846	.88367	.41654
Kolmogorov-Smirnov Z	.764	1.216	.688	.942	.712	1.258	1.178
Asymp. Sig. (2-tailed)	.604	.104	.730	.337	.691	.084	.125

	IISD initiate contact	IISD positive self statement	IISF criticism	IISF opinion	IISF compliment	IISF initiate contact	IISF positive self statement
N	22	22	22	22	22	22	22
Mean	1.8636	2.0136	2.3727	2.9182	3.6636	3.0682	3.0364
Std. Deviation	.75627	.66354	.50538	.59493	.74868	.75048	.64921
Kolmogorov-Smirnov Z	.828	.853	.965	.596	.847	.629	1.096
Asymp. Sig. (2-tailed)	.499	.461	.309	.869	.470	.824	.181

MODERATE (INTELLIGIBILITY)

One-Sample Kolmogorov-Smirnov Test

	Age	Duration PD Months	Duration speech signs Months	Cognition Scale	Apathy Scale	Anxiety Scale	Depression Scale
N	21	21	21	21	21	21	21
Mean	68.90	122.71	58.90	9.10	-26.38	6.90	4.76
Std. Deviation	8.960	52.545	49.544	.944	4.006	3.986	1.841
Kolmogorov-Smirnov Z	.510	.471	1.008	1.190	.727	.521	.845
Asymp. Sig. (2-tailed)	.957	.980	.261	.118	.666	.949	.474

	Mobility Scale	Sentence Intelligibility	FDA Overall	SOCAT Total	SOCAT Leisure	SOCAT Informal	SOCAT Formal
N	21	21	21	21	21	21	21
Mean	2.62	85.466	6.9695	16.48	10.38	3.95	2.10
Std. Deviation	.740	16.1954	.86715	4.118	2.397	1.284	1.609
Kolmogorov-Smirnov Z	1.228	1.289	.808	.818	.911	1.486	1.045
Asymp. Sig. (2-tailed)	.098	.072	.532	.514	.378	.024	.225

	SOCAT Cumulative	Network Total	Inner Circle Total	Middle Circle Total	Outer Circle Total	All close family	All other relatives
N	21	21	21	21	21	21	21
Mean	47.00	25.10	9.19	8.33	10.14	4.00	6.19
Std. Deviation	14.714	11.819	8.750	5.033	6.755	1.789	6.838
Kolmogorov-Smirnov Z	.982	1.019	1.261	1.145	1.116	1.418	1.469
Asymp. Sig. (2-tailed)	.290	.250	.083	.145	.166	.036	.027

	All friends	All other contacts	Interpersonal Discomfort	Interpersonal Frequency	IISD criticism	IISD opinion	IISD compliment
N	21	21	21	21	21	21	21
Mean	12.14	6.24	72.86	94.10	2.6286	2.2619	1.3619
Std. Deviation	6.909	7.402	24.284	17.658	.93656	.85292	.34420

Kolmogorov-Smirnov Z	.583	1.259	.543	.683	.555	.672	.998
Asymp. Sig. (2-tailed)	.886	.084	.929	.740	.917	.757	.272

	IISD initiate contact	IISD positive self statement	IISF criticism	IISF opinion	IISF compliment	IISF initiate contact	IISF positive self statement
N	21	21	21	21	21	21	21
Mean	1.9619	1.8857	2.1667	2.6333	3.4524	2.8429	2.8429
Std. Deviation	.76058	.71714	.54711	.52186	.73595	.65312	.60048
Kolmogorov-Smirnov Z	.672	.796	.657	.786	.723	.712	.540
Asymp. Sig. (2-tailed)	.757	.551	.781	.567	.672	.692	.933

MILD(MOTOR SPEECH/FDA)

One-Sample Kolmogorov-Smirnov Test

	Age	Duration PD Months	Duration speech signs Months	Cognition Scale	Apathy Scale	Anxiety Scale	Depression Scale
N	21	21	21	21	21	21	21
Mean	70.95	93.71	55.43	9.62	-27.10	6.76	4.00
Std. Deviation	7.290	51.424	49.217	.590	3.923	3.404	1.975
Kolmogorov-Smirnov Z	.498	.671	1.031	1.868	.760	.796	.560
Asymp. Sig. (2-tailed)	.965	.759	.239	.002	.610	.550	.912

	Mobility Scale	Sentence Intelligibility	FDA Overall	SOCAT Total	SOCAT Leisure	SOCAT Informal	SOCAT Formal
N	21	21	21	21	21	21	21
Mean	2.29	95.533	7.6648	18.48	11.52	4.33	2.38
Std. Deviation	.717	4.3353	.90525	4.273	2.786	1.278	1.396
Kolmogorov-Smirnov Z	1.910	.976	1.469	.780	.889	.799	.676
Asymp. Sig. (2-tailed)	.001	.297	.027	.577	.408	.546	.751

	SOCAT Cumulative	Network Total	Inner Circle Total	Middle Circle Total	Outer Circle Total	All close family	All other relatives
N	21	21	21	21	21	21	21
Mean	60.05	34.05	10.71	11.43	15.19	4.52	9.43
Std. Deviation	15.721	14.596	8.626	8.091	8.641	1.601	6.831
Kolmogorov-Smirnov Z	.898	.677	1.133	1.079	.987	.915	.990
Asymp. Sig. (2-tailed)	.396	.750	.153	.195	.284	.372	.281

	All friends	All other contacts	Interpersonal Discomfort	Interpersonal Frequency	IISD criticism	IISD opinion	IISD compliment
N	21	21	21	21	21	21	21
Mean	18.14	6.10	70.48	99.67	2.6381	2.1333	1.3619

Std. Deviation	11.842	8.227	23.047	16.427	.87663	.86910	.38791
Kolmogorov-Smirnov Z	.763	1.051	1.178	.731	.880	1.489	1.239
Asymp. Sig. (2-tailed)	.605	.219	.125	.660	.421	.024	.093

	IISD initiate contact	IISD positive self statement	IISF criticism	IISF opinion	IISF compliment	IISF initiate contact	IISF positive self statement
N	21	21	21	21	21	21	21
Mean	1.6714	1.8952	2.2000	2.7857	3.4762	2.9381	2.8524
Std. Deviation	.56227	.59956	.45277	.60687	.78861	.69676	.60878
Kolmogorov-Smirnov Z	.777	.912	.855	.585	.504	.645	.913
Asymp. Sig. (2-tailed)	.582	.376	.458	.884	.962	.799	.375

MODERATE (MOTOR SPEECH/FDA)

One-Sample Kolmogorov-Smirnov Test

	Age	Duration PD Months	Duration speech signs Months	Cognition Scale	Apathy Scale	Anxiety Scale	Depression Scale
N	22	22	22	22	22	22	22
Mean	67.23	123.14	68.05	9.05	-26.41	7.00	4.45
Std. Deviation	9.971	68.324	68.621	.899	3.404	4.386	1.738
Kolmogorov-Smirnov Z	.746	.427	1.170	1.030	.540	.643	.697
Asymp. Sig. (2-tailed)	.634	.993	.129	.239	.933	.803	.716

	Mobility Scale	Sentence Intelligibility	FDA Overall	SOCAT Total	SOCAT Leisure	SOCAT Informal	SOCAT Formal
N	22	22	22	22	22	22	22
Mean	2.73	88.336	6.6373	15.91	10.14	4.32	1.41
Std. Deviation	.631	16.9264	.67370	4.439	2.624	1.644	1.469
Kolmogorov-Smirnov Z	1.424	1.403	.765	1.138	.707	1.133	1.154
Asymp. Sig. (2-tailed)	.035	.039	.601	.150	.700	.154	.139

	SOCAT Cumulative	Network Total	Inner Circle Total	Middle Circle Total	Outer Circle Total	All close family	All other relatives
N	22	22	22	22	22	22	22
Mean	43.41	20.86	7.45	7.45	7.64	3.73	4.82
Std. Deviation	10.455	6.868	4.350	4.056	4.499	1.453	4.239
Kolmogorov-Smirnov Z	.885	.758	.717	1.083	1.341	1.143	.986
Asymp. Sig. (2-tailed)	.413	.614	.682	.191	.055	.146	.286

	All friends	All other contacts	Interpersonal Discomfort	Interpersonal Frequency	IISD criticism	IISD opinion	IISD compliment

N	22	22	22	22	22	22	22
Mean	10.55	3.36	75.23	98.55	2.5409	2.3136	1.4727
Std. Deviation	5.570	3.094	24.125	19.564	.85058	.86040	.37819
Kolmogorov-Smirnov Z	.530	.843	.610	.587	.934	.757	.997
Asymp. Sig. (2-tailed)	.941	.477	.851	.880	.348	.616	.273

	IISD initiate contact	IISD positive self statement	IISF criticism	IISF opinion	IISF compliment	IISF initiate contact	IISF positive self statement
N	22	22	22	22	22	22	22
Mean	2.1409	2.0045	2.3409	2.7727	3.6409	2.9773	3.0273
Std. Deviation	.84496	.76810	.59734	.55135	.70215	.72960	.64452
Kolmogorov-Smirnov Z	.737	.729	.634	.855	.863	.615	.724
Asymp. Sig. (2-tailed)	.649	.663	.816	.458	.446	.843	.672

Appendix 17 Tests of Variance

LEVENE'S TEST FOR EQUALITY OF VARIANCES

	CONTROL - ALL PD		MILD - MODERATE INTELLIGIBILITY		MILD - MODERATE FDA	
	Levene's Test for Equality of Variances		Levene's Test for Equality of Variances		Levene's Test for Equality of Variances	
	F	Sig.	F	Sig.	F	Sig.
SOCAT Total	.028	.867	.394	.534	.003	.956
SOCAT Leisure	.329	.568	.836	.366	.180	.674
SOCAT Informal	.474	.493	3.094	.086	.083	.775
SOCAT Formal	.036	.850	.665	.420	.000	.987
SOCAT Cumulative	.343	.560	.004	.950	1.341	.254
Network Total	.228	.634	.048	.828	9.875	.003
Inner Circle Total	.712	.402	.944	.337	2.399	.129
Middle Circle Total	.003	.955	.784	.381	3.774	.059
Outer Circle Total	.029	.865	.491	.488	7.872	.008
All close family	2.226	.140	.029	.867	.655	.423
All other relatives	1.124	.293	.001	.973	3.295	.077
All friends	.634	.428	2.664	.110	4.877	.033
All other contacts	1.713	.195	.532	.470	7.925	.007
Interpersonal Discomfort	7.395	.008	.314	.578	.601	.443
Interpersonal Frequency	.079	.779	.110	.742	.310	.580
IISD criticism	.229	.634	2.020	.163	.398	.532
IISD opinion	6.446	.013	.123	.727	.903	.348

IISD compliment	.004	.951	.522	.474	.331	.568
IISD initiate contact	13.155	.001	.000	.996	4.379	.043
IISD positive self statement	3.917	.052	.127	.723	3.210	.081
IISF criticism	.002	.965	.041	.841	2.114	.154
IISF opinion	.238	.627	.110	.742	.301	.586
	CONTROL - ALL PD		INTELLIGIBILITY		FDA	
			MILD - MODERATE		MILD - MODERATE	
	F	Sig.	F	Sig.	F	Sig.
IISF compliment	1.183	.281	.275	.603	.285	.596
IISF initiate contact	1.226	.272	.642	.428	.020	.889
IISF positive self statement	1.079	.302	.043	.837	.002	.969

Appendix 18 Topics, ground mapping and examples of content mining questions for semi-structured interviews.

Social life changes

Can you tell me about any changes you've experienced to your social life?

Can you tell me about any changes in the way you interact within these situations?

Causes of change

Is there any particular aspect of your PD that has affected your social life?

How would you say that has changed your ability to socialise?

In terms of (symptom) can you tell me about changes?

Changes to speech

Have you noticed any changes to your speech?

How has your speech been affected?

Reactions of others

How do other people behave towards you?

How does that affect the way that you approach social situations?

Can you tell me more about (e.g. using the telephone)?

What do you mean by (e.g. less independent)?

Could you give me an example of what you mean by (e.g. compensation)?

What would you say is most important to you?

Appendix 19: Example of interview transcription

P52

I: can you tell me about any changes you've experienced to your social life

P: Few if any (1.) (erm) my local activities (1.4) (erm) haven't changed. I've got a very supportive group (2.2) and (..) <name> with her CAB (.) we're also involved (.) I'm indirectly involved (1...) (er) (..) few if any changes

I: so the basic structure of things hasn't changed

P: My my mobility is still good enough to allow me to do the things I was doing two or three years ago

I: and can you tell me about any changes in the way you interact within these situations

P: I'm conscious that my voice at times is (..) that it is it sounds to me at the moment not normal (laughs) sorry (1.) so I'm I'm particularly conscious that my voice has changed (1.) particularly on the telephone (1.0) funnily enough if I have to stand up and do (1..) a powerpoint presentation 'cos I'm involved in that (1.) that I can do (1.) but in normal daily conversation and particularly (..) answering or making phone calls (1.) I'm aware that I I think my voice has changed (1..) and is is (1.) slightly a bit of tremor (..) is not so fluent (1.) and certainly has lost its volume (1...) but but it its impact on my social life and things like that (1..) minimal

I: So you feel that you are willing to engage in interaction

P: Yes (2.) I should perhaps add that (..) the the friends that we've built up here over the last twelve fifteen years since we've lived here (1.) have been marvellously supportive (..) therefore I don't feel (...) in social activities with our existing group of friends (1..) that they in any way (1...) (erm) have a problem with my Parkinson's (..) in fact if anything it's the other way round. They bend over backwards (1..) to compensate (.) where it would help

I: could you give me an example of what you mean by compensate?

P: Oh very easy (erm) not to do with speech necessarily. I race model planes I've always got I know that standing near me one of the people whether I ask him or not is ready to step in and take over so very supportive. In terms of (..) speech (..) I've never had a problem (1..) with them (..) saying I didn't understand what you said (1..) again perhaps because in the (1.) the environment of the group I'm totally about (2.) I can relax (.) I'm not feeling tense (...) your point about on the phone I think there is a degree of (1..) tense on approach (.) therefore since I'm with people I'm comfortable with (..) I think my speech is relatively normal (.) therefore I don't have a problem

I: So on the telephone would you be speaking to people you know or don't know?

P: People (.) both and the speech problem I perceive is worse with people I don't know(3.0)

I: And you mentioned that your speech volume is quieter and more dysfluent. Are there any other changes?

P: Not so much speech but I've (..) I've had a speech therapist come out from <placename> (1.) she was sufficiently comfortable with my speech (..) that she ninety percent of the time that she spent here (..) was to do with swallowing problems (..) food going down the wrong way (1..) is it dysphagia? (1...) (erm) she didn't feel it was worth my doing (...) some of these vocal exercises of oo ee ah (erm) she didn't feel there was any benefit there (...) at that time (...) Lee Silverman wasn't available through <placename>. I don't know if it is now (1.) so no it's (erm) there's really been very little change in that sense

I: and in terms of your mobility can you tell me about changes?

P: (erm) I'm now at the stage with medication I'm certain you know about Parkinson (1.) I was diagnosed eight or nine years ago now (.) for the first four or five years my medication was superb (...) and you wouldn't know I'd got Parkinson's (coughs) but what happens with the drugs I'm on madopar and what have you (1.) a point is reached when the side effects of the drug (...) is actually causing (2.) problems that are as bad as Parkinson's itself so I get a lot of uncontrolled movement (1.) (er) (...) a lot of that's exaggerating (2.) I now have a period about say one or two hours after taking (..) my drugs and I take them three times a day (1.) when the physical (1..) (erm) (1.) result of taking the drugs (1..) is jerking legs (er) affect on my speech slightly (..) so I I'm getting more of a hassle from (1.) the side effect of the drugs (1.) than I used to get from Parkinson's alone

I: and does that affect all parts of your body?

P: Yes (2..) worst is my left leg (erm) (3.0) speech (er) swallowing can be quite a problem (1...) the speech therapist gave me a medication (..) which I understand is to slow it going through my mouth (...) so the (1.) valve has time to close before the food gets near it (2..) I haven't used that yet but (erm) I certainly have problems coughing (.) fits at times where things have gone down the wrong way (2.) so that has got worse

I: So have there been any ways in which those physical changes have had an effect on activities you can take part in?

P: No (1..) I I'm very lucky I think that my relatives and friends (2..) just accept that (2..) if I'm jerking a bit that's it there's no (1.) I'm not aware of any impact on my social life (1.) which comes from speech problems (1.) I'm conscious of the

point you made today (1...) that when I'm under stress my symptoms are worse (.) and my speech is worse (1...) although I am a bit more anxious about my ability to do speaking (..) I'm damned if it will stop me doing something I believe is worth doing (...) while I can I will. You can either make yourself miserable or (.) if not make yourself happy. I think there's an element in every illness (.) and I'm very lucky Parkinson's isn't that bad (..) but I think there's an element in any situation where (..) if you want to be miserable you can make yourself miserable as easy as pie (..) there is an element of you can choose which way it goes

I: and has there been any impact from the other physical changes?

P: No because (...) (erm) (1.) I've recently (1..) well I see my neurologist over in <placename> (..) once a year (..) I've seen him recently (..) I've had to renew my three year driving licence on the basis of that (..) he is perfectly happy (1...) the slight jerkiness I get (..) or the jerkiness (1.0) dyskinesia after taking the drugs (1..) doesn't seem to (1.0) affect my driving particularly at all (2...) largely because as I understand it (2.) within the brain as I understand it are automatic skills which you have developed prior to Parkinson's remain (.) largely unaffected (1.) but the ability to take on new skills (1..) is compromised (1...) therefore if I want wanted to become an airline pilot I'm being ridiculous (...) the fact that I hadn't learned prior to Parkinson (2.) would make that more difficult if not impossible (1...) but on the things like driving (1...) (erm) it's made no difference. I have a physical (..) limitation now on sheer distance walked (...) I did a charity walk two years ago ten miles no problem (1.) I think I'd struggle to do ten miles now (2.) and the other thing I get I get a lot of muscle stiffness and pain (1..)

I: so is there anything else you would like to add?

P: (..)no I think that's about it really

End

Appendix 20 Raw Data

	SPMSQ	LARS	HADS Dep	HADS Anx	SOCACT total	NETWORK total	T satisfaction	SOCACT Leisure	SOCACT Informal	SOCACT Formal	NET Inner	NET Middle	NET Outer	NET close family
C1	10	-21	5	1	17	38	2	12	3	2	19	8	11	3
C2	8	-32	7	1	17	20	2	12	4	1	7	7	6	1
C3	10	-31	6	3	22	49	2	13	5	4	12	13	24	4
C4	10	-28	3	3	14	25	1	11	2	1	7	2	16	3
C5	10	-29	6	6	17	63	1	10	4	3	7	2	54	3
C6	10	-29	1	2	24	59	2	17	4	3	13	35	11	2
C7	10	-28	5	4	14	26	2	10	2	2	8	11	7	5
C8	10	-30	0	3	11	16	2	11	0	0	5	3	8	5
C9	9	-23	3	0	16	19	1	11	4	1	7	11	1	7
C10	9	-29	5	1	18	30	2	13	3	2	8	13	9	5
C11	10	-29	3	1	25	36	3	14	5	6	17	16	3	1
C12	10	-26	3	5	16	23	2	12	2	2	3	16	4	1
C13	10	-28	3	2	20	18	2	13	4	3	3	6	9	3
C14	10	-30	4	0	19	53	2	10	4	5	15	15	23	6
C15	10	-27	3	1	17	36	2	11	3	2	8	9	19	3
C16	10	-33	3	2	18	48	2	12	5	1	18	22	8	4
C17	9	-27	8	2	13	27	2	11	2	0	9	9	9	3
C18	10	-35	6	1	20	23	1	11	6	3	6	2	15	4
C19	9	-27	4	2	18	18	2	10	6	2	10	8	0	1
C20	10	-29	5	1	18	23	2	12	4	2	11	5	7	3
C21	10	-27	0	0	17	20	2	11	4	2	5	10	5	5
C22	9	-28	9	5	16	22	1	12	3	1	8	12	2	4
C23	10	-24	7	3	14	13	2	11	2	1	1	4	8	2
C24	10	-31	6	2	22	17	2	10	11	1	6	5	6	3
C25	8	-31	3	2	21	23	2	14	4	3	9	10	4	2
C26	10	-31	2	2	20	19	2	16	4	0	2	9	8	2
C27	10	-28	9	5	13	14	1	10	2	1	8	2	4	14
C28	10	-31	12	2	30	22	2	18	6	6	5	8	9	1
C29	10	-32	5	1	26	21	2	17	5	4	6	6	9	4
C30	9	-29	7	3	20	21	2	13	5	2	11	3	7	5
P2	9	-22	3	4	20	29	1	10	6	4	8	9	12	8
P3	10	-23	6	7	3	12	1	3	0	0	3	2	7	4
P4	8	-23	3	6	14	18	1	10	3	1	4	6	8	2
P5	10	-26	2	4	10	19	1	8	2	0	14	3	16	4

	SPMSQ	LARS	HADS Dep	HADS Anx	SOCACT total	NETWORK total	T satisfaction	SOCACT Leisure	SOCACT Informal	SOCACT Formal	NET Inner	NET Middle	NET Outer	NET close family
P6	8	-31	13	6	17	22	1	11	5	1	9	5	8	5
P7	10	-28	14	2	18	37	1	11	4	3	22	8	20	5
P8	9	-23	17	6	16	16	1	11	3	2	4	6	6	3
P9	10	-24	9	7	18	45	1	12	5	1	5	11	29	4
P10	10	-24	1	4	20	38	1	12	4	4	21	13	4	4
P11	10	-23	10	6	13	28	2	7	3	3	15	7	7	4
P12	10	-26	5	8	18	13	2	12	4	2	2	5	21	2
P13	10	-30	8	3	18	26	1	9	4	5	7	12	18	3
P14	9	-24	4	1	17	27	2	10	6	1	15	9	14	4
P15	10	-32	7	4	21	44	1	16	5	0	7	17	18	4
P16	9	-31	5	3	12	54	2	7	2	3	42	5	5	7
P17	10	-32	10	2	19	11	1	12	6	1	3	4	4	2
P18	9	-21	10	6	17	19	1	10	4	3	3	8	18	3
P26	10	-29	4	3	29	41	2	16	6	3	8	8	25	6
P35	10	-23	4	0	19	32	1	11	4	4	5	17	10	5
P36	10	-22	5	6	19	15	1	12	5	2	5	2	10	3
P37	10	-29	8	2	23	33	2	14	4	5	15	6	11	4
P38	10	-35	13	3	15	44	1	10	4	1	9	18	17	4
P39	10	-24	10	5	17	25	2	11	3	2	4	10	11	7
P40	10	-26	4	6	15	22	1	9	5	1	11	8	3	6
P41	10	-24	2	2	14	19	1	8	4	2	10	4	6	8
P42	10	-32	3	3	18	23	2	11	5	2	9	4	11	6
P43	10	-32	7	4	17	63	2	11	2	4	14	38	10	3
P44	10	-31	7	5	18	66	1	12	4	2	7	19	40	5
P45	9	-30	10	5	15	29	1	10	4	1	9	13	7	3
P46	9	-28	8	4	21	21	1	11	6	4	6	11	4	4
P51	9	-26	10	4	14	26	2	8	6	0	10	9	7	4
P52	9	-25	6	5	27	29	1	17	8	2	7	15	8	5
P53	9	-26	2	3	28	31	2	18	6	4	9	11	23	5
P54	9	-28	7	3	14	15	2	9	5	0	4	6	5	2
P55	10	-27	4	4	14	22	1	7	7	0	5	4	13	4
P56	10	-29	5	4	17	20	1	11	3	2	7	6	7	3
P57	9	-27	9	5	20	21	1	13	4	3	10	21	10	3
P58	9	-22	8	5	14	17	1	9	4	1	4	5	8	1
P59	10	-33	1	4	18	22	2	13	5	0	11	6	5	4
P60	9	-25	6	6	17	29	2	12	4	1	9	14	6	4
P61	10	-27	4	1	14	26	2	10	4	0	9	11	6	3
P63	9	-22	16	3	14	8	2	10	4	0	3	2	3	4

P64	10	-25	6	8	16	17	1	11	4	1	5	6	6	3	

	NET relations	NET friends	NET other	IIS Discomfort	IIS Frequency	IISD criticism	IISD opinion	IISD compliment	IISD initiate	ISSD self statement	IISF criticism	IISF opinion	IISF compliment	IISF initiate	ISSDFself statement
C1	6	10	19	98	86	4.3	3.1	1.2	1.7	2.7	1.2	1.4	4.2	3	3.3
C2	4	15	0	68	122	2.4	2.4	1	1.7	1.4	3	3.3	4.6	3.6	3.4
C3	16	19	10	61	113	2.7	1.4	1	1.6	1.6	2.2	3.1	4.2	3.6	3.6
C4	4	13	5	85	86	3.6	2.9	1	1.7	2.3	1.7	2.7	3.4	2.6	2.7
C5	4	54	2	42	137	1.3	1.1	1.2	1	1.3	3.6	4	3.4	4.1	3
C6	1	25	31	48	115	1.6	1.3	1	1.6	1.3	2.3	3.3	3.4	3.1	3.1
C7	4	6	11	63	84	2.3	1.4	1.6	1.3	2.1	1.7	2.6	2.8	3	2.3
C8	3	4	4	61	85	2.4	1.9	1.2	1.6	1.3	1.6	2	3.8	2.4	3
C9	6	6	0	60	95	1.6	2	2.2	1.4	1.6	2	2.1	3	3.9	2.9
C10	8	4	13	46	109	1.3	1.3	1.2	1.4	1.3	2.7	2.9	3	3.6	3.1
C11	4	31	0	91	107	4	3	1.4	1.3	2.6	2.1	2.4	4.2	3.9	3.3
C12	0	22	6	58	97	2.9	1.4	1	1	1.4	2.1	2.7	3	3.3	2.9
C13	10	4	1	63	98	2	1.9	1.4	1.6	2	2.4	2.7	3.4	3	2.7
C14	11	35	1	51	113	2.2	1.3	1	1	1.4	2.4	3.3	3.8	3.7	3.3
C15	5	10	18	88	101	3.1	2.9	1.8	2	2.4	2.1	2.9	3.6	3.4	2.9
C16	18	24	2	51	124	2.2	1.7	1	1	1	2.4	3.1	5	4	3.9
C17	6	18	0	76	97	2.3	2.6	2	2	1.9	2.4	2.6	3.6	2.6	3.4
C18	2	17	0	68	120	3.4	1.9	1	1	1.7	2.6	3.7	4.2	3.6	3.6
C19	0	15	2	38	88	1.2	1.1	1.4	1	1.3	2	2	3.2	3	3
C20	4	7	9	56	98	1.9	1.7	1	1.6	1.6	2.2	2.7	3.6	2.6	3.3
C21	0	15	0	39	119	2.9	2	1.8	1.9	2.9	1.7	2	4	3	2.7
C22	0	7	11	56	104	2.2	1.9	1.2	1.3	1.1	2.3	2.1	4.2	2.7	4
C23	1	1	9	65	97	2.9	1.7	1.4	1.1	1.6	2.2	2.7	3.2	3.1	2.9
C24	2	8	4	64	113	2.7	1.3	1.2	1.6	2	2	3.1	3.8	3.4	2.9
C25	13	8	0	78	125	3.1	2.4	1.6	1	2.6	3.1	3	4.2	4.7	3.1
C26	2	15	0	66	111	3	2.1	1	1.3	1.4	2.2	2.9	4.4	2.9	4.1
C27	5	5	1	61	120	2	1.9	1.6	1.4	1.7	3	2.7	4.2	3.4	3.4
C28	5	6	10	67	105	2.6	2	1.2	1.7	1.9	2.1	2.9	4.2	3.4	3
C29	6	11	0	52	129	2.2	1.4	1	1	1.6	2.8	2.9	4.8	3.9	4.4
C30	14	2	0	82	82	3.1	2.6	2	1.4	2.3	1.2	1.9	3.4	3	2.9
P2	4	17	0	62	81	2.2	1.7	1.2	1.9	1.6	2	2.1	2.8	2.4	2.4
P3	2	3	3	36	54	1	1	1	1	1.1	1	2	1.8	1	2.1

	NET relations	NET friends	NET other	IIS Discomfort	IIS Frequency	IISD criticism	IISD opinion	IISD compliment	IISD initiate	ISSD self statement	IISF criticism	IISF opinion	IISF compliment	IISF initiate	ISSDFself statement
P4	4	11	1	46	71	1.8	1.3	1	1.1	1.1	1.2	2.1	3	2.3	2
P5	11	18	0	80	88	3.3	2	1.4	1.7	2.4	1.6	2.9	3.5	2.9	2.9
P6	2	9	7	105	89	3.1	3.3	1.4	3.4	3.3	2.3	3	4.2	3.3	2.7
P7	17	28	0	77	105	2.8	2.1	1.4	1.9	2.3	2.4	2.6	2.6	2.4	2.7
P8	2	3	8	105	89	3.1	3.4	2	3.4	2.9	3.2	3.3	3.4	2.6	2.7
P9	4	5	32	113	106	4.1	3.6	1.4	3.1	3	2.6	3.1	4.6	2.3	4
P10	13	15	6	78	112	3.1	2.7	1.2	2.9	1.1	1.8	2.4	4	2.7	3.2
P11	13	11	1	131	91	4.8	4	2.6	2.9	3.1	1.9	2.6	3.2	2.7	3.1
P12	4	17	5	105	86	4.1	3.7	1.8	2.1	2.6	2	2.4	3	2.9	2.3
P13	5	20	9	64	123	2	2.6	1.4	1.6	1.4	2.9	2.4	4.4	4	4.3
P14	13	21	0	67	89	2.4	2	1.4	1.7	1.7	2.2	2.3	3.4	2.4	2.7
P15	13	17	8	60	94	2.6	2.1	1.2	1.5	1.5	2.4	2.3	3.4	2.9	3
P16	31	14	18	62	105	2.6	2.1	1	1.3	1.7	2.8	3.3	3.8	3.3	3
P17	3	4	2	105	89	3.1	3.3	1.4	3.4	3.3	2.1	2.3	3.8	2.3	2.7
P18	4	16	6	52	72	1.9	1.4	1.4	1.7	1.6	2.3	2.3	3	2.7	2
P26	20	1	12	43	132	1.2	1	1	1	1.3	2	4.3	4.6	4	2.7
P35	5	19	3	58	83	2.1	1.7	1	1.1	2	2	2.7	3	2.9	2
P36	4	5	5	96	98	2.8	3.7	1.8	2.3	2.9	2	3	4	2.6	3
P37	11	12	5	79	94	3.2	2	1.4	1.9	2.3	1.8	2.3	3.8	3.3	2.6
P38	6	20	14	68	118	2.9	1.9	1.2	1.4	1.9	2.1	3.6	4.2	3.9	3
P39	6	11	2	60	91	2	2	1.4	1.6	1.5	2.2	2.3	3.4	2.7	3.1
P40	1	15	0	50	132	1.3	1.3	1	1.9	1.6	2.8	3.8	4.3	3.9	4.8
P41	4	5	3	49	85	1.2	1.4	1.2	1.7	1.4	2.7	2.6	2.5	2.4	2.3
P42	6	12	0	62	101	2.6	2.1	1	1.3	1.7	2.1	2.7	4	3.6	2.6
P43	7	53	0	66	104	2.6	1.7	1.8	1.6	1.6	2.3	2.9	3.4	3.1	2.7
P44	12	33	16	65	113	2.9	1.6	1.4	1.4	1.6	2	3.4	3.8	3.9	3.6
P45	3	20	0	86	105	2.7	2.9	2	2.1	2.6	2.8	3.3	3.8	3.3	3
P46	3	12	2	101	102	3.4	3.3	2	2.4	2.9	2.8	3.1	3.4	2.7	2.7
P51	4	12	6	64	94	2.3	1.9	1.4	1.3	2	2.3	1.9	1.4	1.3	2
P52	11	14	0	71	102	3.1	2.1	1.4	1.4	1.6	2.2	2.9	4	3	3
P53	8	30	0	40	141	1.3	1	1	1.1	1.1	3.6	3.6	4.8	4.1	4.4
P54	8	5	0	102	108	2.9	3.4	2	3.3	2.7	2.8	3	4	2.7	3.3
P55	6	12	0	73	98	2.4	1.9	1.6	2	1.9	2	2.4	4	3.6	3.1
P56	5	7	5	38	102	1.2	1	1	1.1	1	2.4	2.9	3.6	2.6	3.4
P57	6	32	0	56	96	2.1	1.6	1.2	1.6	1.3	2.3	3	2.8	2.7	3
P58	0	12	4	90	110	3.2	2.9	1.8	2.3	2.3	2.7	3.1	3.8	3.1	3.3
P59	5	9	4	58	102	2.3	2.1	1	1.1	1.4	2.2	2.4	4	3.6	3.1
P60	15	9	1	84	103	3.4	3	1.2	2	1.7	2.3	2.9	3.4	3.1	2.7

P61	1	14	8	44	138	1.8	1	1.2	1.1	1	3.3	3.7	4.8	4.6	3.7
P63	2	2	0	114	67	4	3	2.2	3.6	3	1.1	1.4	2.4	2.4	2.6
P64	0	8	6	70	98	2.4	1.9	1.6	2	1.9	2.2	2.9	4	3	3