Cardiff Metropolitan University

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B.Sc. (Hons) Speech and Language Therapy

The spouses’ experiences of a Parkinson’s disease voice support group: An interpretative phenomenological analysis.

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Dissertation submitted in partial fulfilment of the requirements of Cardiff Metropolitan University for the degree of Bachelor of Science
DECLARATION

I hereby declare that this dissertation is the result of my own independent investigation under the supervision of my tutor. The various sources to which I am indebted are clearly indicated. This dissertation has not been accepted in substance for any other degree and is not being submitted concurrently for any other degree.

Candidate’s signature: [Signature]

RESEARCH DATA PRIVACY

I acknowledge the issue of research data privacy and undertake not to share research data in any form without the explicit approval of their supervisor.

Candidate’s signature: [Signature]
Acknowledgements

Firstly, I would like to thank [redacted] for her continued support and advice throughout this year. Without her help, this project would not be possible.

Secondly, to my participants: [redacted] Thank you for taking your time to help me with this project, and sharing your experiences of Parkinson’s disease with me so openly and honestly.

And finally, my family and friends. Thanks to my flatmates and course mates for their love and support over the past four years; I would not have got through it without you. To my family, in particular my Mum, who has never given up on me.

And to [redacted] for your patience and love throughout this year, and for keeping my spirit up.
Abstract

**Background:** Parkinson’s disease is the second most prevalent neurodegenerative disease in the UK. Along with difficulties with mobility and balance, the majority of people with PD (PWPD) will have a deterioration in voice loudness and communication. A deterioration in communication can lead to a negative self-perception and difficulties forming relationships and support networks for the individual, whilst spouses often develop a caregiver burden and feeling of responsibility.

**Aims:** This study aims to explore the experiences of a PD voice support group from the perspective of the spouse. This will clarify whether attending a PD-specific group has any potential benefits for the spouse in terms of coping in daily life, adjusting to the inevitability of living with a neurodegenerative condition and changes to support networks and friendship.

**Methods and Procedures:** The study adopted a qualitative methodology to elicit the spouses’ experiences related to the study aim. In order to carry out an in-depth analysis of the data, an interpretative phenomenological analysis (IPA) was chosen, using semi-structured interviews as the method of collecting the data. The sample included three wives of husbands who had PD and who attended the support group.

**Outcomes and Results:** The analysis of the interviews uncovered themes that were evident in all or some of the participant’s accounts. Results collated the wives’ experiences into six superordinate themes: burden, types of comparison, catalyst for change, facing inevitability positively, mutual trust and friendship and dependence.

**Conclusions and Implications:** This study’s findings have highlighted similar themes related to burden and peer support from the spouses’ experience. In addition, it has been successful in adding to the currently limited evidence base of the experiences of spouses in living with progressive neurological conditions. Further research could consider the effectiveness of voice support groups in terms of social participation and potential impairment-based voice management for PWPD via a scaling-based methodology.

**Key Words:** Parkinson’s disease; Support groups; Spouse experience; Voice management; IPA

* (International Journal of Language and Communication Disorders)
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1. **Introduction**

This study is an exploration of the experiences of a Parkinson’s disease (PD) support group aimed at voice loudness, from the spouses’ perspective. Due to the support group’s specific nature of targeting voice, as well as this study’s focus on the spouses’ perceptions, studies mirroring this are limited.

Investigating the perceptions of a PD support group through the eyes of the spouses will uncover the consequences of a support group on the spouse and the marital relationship, as well as better understand the influence on daily living and coping with a degenerative condition. A comprehensive insight into this will aid in future considerations of the use of voice-specific support groups within the Speech and Language Therapy (SLT) management of PD, which is currently limited. It will also give the reader a better appreciation of the impact of a degenerative condition on the PWPD’s closest support networks, and signpost to further exploration in spouse wellbeing.

The subsequent literature review will aim to clarify the current research related to PD, including the impact on voice, PD-specific voice management, as well as the effectiveness of generic support groups on chronic medical and neurological conditions.
2. Literature review

2.1 Parkinson’s disease (PD)

PD is a chronic neurological progressive condition, and is a result of a gradual reduction in dopamine levels within the substantia nigra of the basal ganglia (Yorkston, Miller, Strand and Britton, 2013). PD affects around 130,000 individuals living in the United Kingdom, with an estimated incidence of 18,461 in 2018 (Parkinson’s UK, 2018). PD is the second most prevalent chronic neurodegenerative condition in people over the age of sixty (Parkinson’s UK, 2009).

The disease is typically categorised by an impairment in mobility, cognition, communication and emotional well-being (Kessler and Liddy, 2017). Diagnostic features of PD are predominantly related to mobility. These include postural instability, bradykinesia (slow movement), rigidity, a resting tremor and freezing (Blitzer, Brin and Velickovic, 2011). Identification of two of these five of these cardinal features results in a PD diagnosis.

2.2 The effect of PD on communication

PD is associated with hypokinetic dysarthria, a motor speech impairment characterised by a limited variability in loudness and pitch of voice (Holmes, Oates, Phyland and Hughes, 2000), a harsh and breathy voice quality (Constantinuescu, Theodoras, Russell, Ward, Wilson and Wootton, 2009), a variable rate of speech and imprecise articulation of consonants (Theodoras, 2011).

A deterioration in an individual’s communication is often unavoidable for people with the disease, with 80-90% experiencing changes in their communication through the course of the disease, in particular within phonation (Miller, Noble, Jones and Burn, 2006). The experiences of dysarthria have been explored from the perspective of the individual via semi-
structured, interpretative interviews (Miller et al, 2006; Walshe, Peach and Miller, 2009). Dickson, Barbour, Rosaline, Brady, Clark and Paton (2008) found that beyond the surface diagnosis of hypokinetic dysarthria, participants reported difficulties with forming relationships, as well as an interpreted negative self-perception and stigmatisation as a result of their communication impairment.

2.3 Self-perceived communication changes in PD

A negative change to an individual’s ability to communicate can be detrimental to their psychological well-being and sense of autonomy. A deterioration in the satisfaction of communication has been discovered to occur in over 90% of people with Parkinson’s disease (PWPD), irrespective of disease severity or progression (Holmes et al, 2000).

A breadth of research has recognised the self-perceived communication changes as a result of PD (Holmes et al, 2000; Miller, Noble, Jones, Allcock and Burn, 2008). Miller et al (2008) explored the self-perceived changes in communication associated with PD via semantic differential style questionnaire. The questionnaire consisted of 22 bipolar adjective pairs (e.g. ‘talkative’ and ‘quiet’) which were rated on a 7 point scale. All 104 participants had a formal PD diagnosis, and had no pre-morbid communication or cognitive difficulties prior to diagnosis. A significant perceived deterioration in communication after the onset of PD was reported, with negative feelings surrounding communication as universal in scope across participants, irrespective of age and gender. A weak relationship was ascertained between the disease’s severity and the perceived impact; this was related to a reduced confidence in initiating conversation, affecting their self-perception of being an independent and autonomous communicator. These findings, however, are based on quantitative data collated from questionnaires, in order to measure change prior to a formal PD diagnosis (‘before’) and at the time of data collection (‘now’). The use of semantic differential (SD) scales as a measure of
rating inhibits organic experiences to be generated by the participants, and may not be representative of negative associations with the disease. A qualitative, interpretation of feelings and experiences would be more beneficial in understanding the underlying negative associations with the individual’s communication, as well as considering the experience of the PWPD’s closest support networks.

2.4 Management of voice loudness in PD

The typical management of hypokinetic dysarthria adopted by Speech and Language Therapists (SLTs) often addresses the phonatory impairments, particularly breathiness and reduced loudness (Freed, 2011). The Lee Silverman Voice Treatment (LSVT®) is a long-standing technique used amongst SLTs to manage voice loudness and intelligibility within the client group of Parkinson’s disease (Wight and Miller, 2015). The aim of the programme is for individuals to ‘speak loud’ and to self-monitor phonatory and respiratory effort (Sapir et al, 2007).

An intensive and direct treatment aiming to increase vocal loudness, LSVT® has been recommended by the National Institute for Health and Clinical Excellence (NICE) as a particular management technique for optimising intelligibility of speech and improving vocal loudness within the PD client group (NICE, 2017). The recommended intensity of the programme is 4 x 1 hour sessions over 4 weeks (Ramig et al, 2001).

Evidence has suggested that whilst LSVT® directly targets vocal loudness, associated positive effects has also been observed within vowel articulation and intelligibility of the acoustic signal as a result of the treatment (Sapir et al, 2007). The benefits from LSVT® in relation to vocal loudness have been demonstrated to be maintained long-term. Ramig et al (2001) concluded that LSVT® significantly increased sound pressure levels of 33 participants
with PD when assessed immediately after the therapy. These effects were maintained 2 years post-treatment.

The effectiveness of LSVT®’s application within a group therapy has been explored. Searl et al (2011) discovered that LSVT® exercises could be adapted for use within a group therapy setting, with 80% of participants demonstrating louder voices after one 90 minute session for an 8 week block (total of 720 minutes). This suggests that the use of voice therapy within a group context can be beneficial for its members, in terms of an increase in objective sound levels. However, the efficacy of this programme in regards to the psychosocial benefits (e.g. client satisfaction, reduced anxiety) of group voice therapy was not explored. This gap in research is reflective across the LSVT® evidence base, with a focus often on impairment-based outcomes (NICE, 2017).

Further challenges exist within LSVT®’s delivery. SLTs must complete a LSVT® training course in order to carry out the intervention, requiring expenses to do so (Ebersbach, 2014). The intense nature of the programme depends heavily on high levels of motivation from the clients (Herd et al, 2012). The extent of the carryover of acquired skills within the intervention into everyday communication also remains unclear (Eberschbach, 2014).

2.5 Psychosocial impact of PD

Individuals with PD often present with significantly high levels of mental health problems, particularly depression, when compared to their age-matched population (Garlovsky, Overton and Simpson, 2016). Percentages vary, with some researchers suggesting 35-40% of individuals have depressive symptoms (McDonald, 2008; Sagna, Gallo and Pontone, 2014).

Schrag, Jahanshahi and Quinn (2001) deduced that depression in people with Parkinson’s disease is related to the severity and progression of their disease, recent deterioration in motor symptoms and falls. This was later supported by Stella, Banzato,
Quagliato and Viana (2008), who concluded that individuals with PD who are medically more advanced in their disease displayed depressive symptoms and demonstrated a reduced functional capacity within their activities of daily living. However, this assumption is not exclusive to those in the last stages of the disease, with depression apparent across all stages of the disease’s progression (Moore and Seeney, 2007).

2.6 Spouses and PD

The spousal relationship can be negatively affected as a result of PD. As the disease progresses and worsens in severity, the role of ‘caregiver’ becomes more dominant (Peters, Fitzpatrick, Doll, Playford and Jenkinson, 2011), as there is an increased need of support for activities of daily living (Williamson, Simpson and Murray, 2008). Often this role is left to the individual’s spouse. Spouses that serve as caregivers have demonstrated increased levels of depression, anxiety and sense of burden as the disease progresses (Hirsch, Sanjak, Englert, Iyer and Quinlan, 2014).

The understanding of the benefits of support groups remains an issue for spouses of people with Parkinson’s disease (PWPD). McLaughlin et al (2011) demonstrated via interviews with 17 spouses of PWPD that spouses have a limited understanding of the potential benefits of support groups in reducing burden for both them and their partner with PD, whilst are concerned of their increasing caregiver role.

Hasson et al (2010) explored the experiences of carers with Parkinson’s disease within palliative care. Within the later stages of the disease, caregivers exhibited thoughts of adopting multiple roles, and experienced a lack of guidance and knowledge around the care needed. In addition, feelings of helplessness and loss of control were also prominent.

An exploration of the caring experience of relatives with PD via semi-structured interviews demonstrated a significant social and emotional burden for both caregiver and
individual (McLaughlin et al, 2011). Peters et al (2011) explored the association between patient self-reported health and carer strain through the use of self-reported carer questionnaires. It demonstrated that an increased perception of caregiver strain and decreased emotional well-being is related to limited physical mobility and social difficulties. However, due to the adoption of questionnaires within their methodological design, only an association could be validated. A qualitative methodology examining the lived experiences via interview may have provided the researcher with a more organic perception of caregiver strain.

An experience of uncertainty within the illness’ progression has been explored within the literature. Hurt, Cleanthous and Newman (2017) explored the experiences of 18 spouses in relation to illness uncertainty; the spouses demonstrated uncertainty within symptoms and prognosis, medical and self-management, social functioning and impact, demonstrating the diverse impact of uncertainty which spans beyond impairment-based concerns.

Literature has begun to emerge, in particularly within the written memoirs of spouses. Atwood, Hunnewell and Saucier’s (2005) account of living with PD explored the changing roles of a spousal relationship after a PD diagnosis. The authors reinforce the joint responsibility exhibited by both spouse and the individual with PD, as well as the commitment of marriage, in which: ‘we have it, and we will cope with it together’ (p101). The spouse is also emphasised as helping the individual retain self-identity and establishing a balance between the disease and ordinary daily life.

The daily consequence of living with PD as a family unit has been explored using phenomenological analysis, in order to extract themes of experiences of individuals closest to the disease. Smith and Shaw (2017) generated themes around the importance of kin support (‘being together with PD’), and the sense of belonging and social engagement created within support groups. The participant emphasised group support as a source of companionship, as well as a platform for sharing disease-specific information, which helped members maintain control and independence within daily life. However, this research is based on interviews from a
mixture of PWPD and their spouses, with a total of nine participants. It uses a higher number of participants expected for a typical IPA study, which prevents the study from considering each participant in detail within their experiences. In addition, the mixed sample skews the research question, in terms of the reader having difficulties identifying the spouses or PWPD’s experience clearly.

2.7 Support networks and PD

Little research considers the role of support networks within progressive neurological conditions, however, in particular related to outcomes of communication impairment. However, support groups have been examined in relation to issues with mobility, and has begun to explore the indirect gains in social support. Ribeiro Artigas et al (2015) examined the quality of life, depression and anxiety levels of 20 individuals who attended a PD support group. Results demonstrated a significant increase in quality of life and lower scores of depression as a consequence of support group attendance.

This evidence was reinforced by Sheehy, McDonough and Zauber (2016), who deduced that the 20 individuals who attended a PD exercise group demonstrated self-perceived improvements in physical health, as well as reported experiences of reduced anxiety and social barriers. This demonstrates that despite a different focus in primary impairment, often similar themes can be extracted related to participation and activity domains.

Stanley-Hermanns and Engebretson (2010) examined the experiences of individuals with PD in relation to their progression through the disease and daily challenges, as well as their surrounding social networks via ethnography. Due to the unknown aetiology and complexity of PD, themes regarding coping and social isolation were prominent from analysis, irrespective of severity or progression of disease.
The concept of support has been explored from the couple’s perspective within the nursing literature. Bigersson and Edberg (2004) explored the PWPD and their spouse’s experience of receiving support. The couples commented on the change in dimensions of their relationship, and demonstrated that support ensured receiving respectful and dignified support complimented their spousal relationship.

2.8 Holistic management of neurological conditions

The consideration of the wider management of communication disorders has been considered within the field of aphasiology and progressive neurological conditions, in particular in relation to the International Classification of Functioning (ICF) domains (WHO, 2001). The development of the Living with Aphasia: Framework for Outcome Measurement (A-FROM) considers the management of aphasia in terms of addressing impairment, environment, participation and personal factors (Kagan, 2011). The ‘participation’ domain considers the individual’s personal relationships, and the effect of these on daily living.

Whilst communication management for neurological disorders can often focus on improving the impairment, the consideration of the wider social and functional impact of a progressive neurological disorder is now emerging. Power, Anderson and Togher (2011) concluded that, in the context of Huntington’s disease, the World Health Organisation International Classification Function domains (World Health Organisation, 2001) can be used to aid goal setting and consider the management of communication related to activity and participation limitations. As a result, a person-centred and holistic approach to communication is being considered. This can be applied to Parkinson’s as a neurodegenerative disease that is multi-factorial and complex in presentation. As a result, it is important to consider the individual’s holistic communication and the result on daily activity and participation, which includes the individual’s closest social networks (i.e. the spouse).
2.9 Effectiveness of support groups for spouses

The use of groups as facilitators for peer support access and a coping mechanism has been explored for individuals with acquired neurological conditions and their caregivers, in particular within the domain of aphasia (Tregea and Brown, 2013). Lanyon, Worrall and Rose (2017) explored the experiences of individuals attending a community aphasia groups via qualitative interviews. Analysis revealed the value of the group in supporting others and the sense of belonging, alongside developing new social networks. Whilst support groups are a salient support network for individuals, it is also important to consider their effectiveness for the spouse.

A breadth of literature exists examining the experiences of spouses with breast cancer in relation to support groups. Core themes taken from qualitative interviews include providing a space for support with emotional coping for the marital relationship, including improved functional ability and a positive adjustment to daily life (Levy, 2011; Hasson-Ohayon, Goldzweig, Dorfman and Uziely, 2014).

Current literature demonstrates the effectiveness of support groups for spouses for a range of medical conditions associated with communication, particularly within dementia. O’Connell et al (2014) evaluated the use of telehealth support groups for individuals with atypical early-onset dementias within rural regions of Canada. Whilst discussing benefits of the group in terms of socialisation and support, a spouse-specific group for a specific condition ensured that the opportunity to discuss disease-specific issues and advice was paramount for the group to be effective. Diehl, Mayer, Förstl and Kurz (2003) investigated the experiences of spouses who attended a support group for those affected by frontotemporal dementia. Themes arose related to an adjustment for the spouse in daily life, as well as emphasised the importance of disease-specific considerations in discussions within the group meetings.
Chu et al (2011) investigated the effects of a support group on the spouses of individuals with dementia in terms of perceived burden and depression. The use of quantitative scaling and qualitative interviews demonstrated reduced perceived depression, but did not demonstrate efficacy for relieving burden. However, qualitative interviews demonstrated themes of supporting spouses with information and providing a social network. This research is limited, however, within its scope: the small sample size and mixed methods approach to data collection convolutes the outcomes and purpose for this study as an investigation into the experiences. As a Taiwanese study, its application within British support groups can be disputed additionally. As a result, more research within British PD support groups, as well as other degenerative conditions would be useful in establishing their impact on the spouse.

2.10 Qualitative research within PD and neurological conditions

Within the field of chronic neurological condition, there is a lack of qualitative research. An emphasis continues to exist around quantitative data created by the biomedical model, in which specific strategies are examined in order to create better outcomes. A shift towards understanding the organic, lived experiences of individuals with PD has emerged within literature, in order to explore their daily needs and wishes (Bramley and Eatough, 2005; Caap-Ahlgren and Dehlin, 2001). Limited qualitative research is available that focuses on the spouses’ experiences, particularly within chronic neurological conditions.

Gaps exist in the knowledge and experiences of individuals and their caregivers with chronic neurological diseases, with qualitative researchers’ often favouring conditions with a clear management and cure e.g. breast cancer, diabetes. Often neurological conditions are overlooked due to their unpredictable course and associated cognitive difficulties (Audulv, Packer and Versnel, 2014). However, adopting a qualitative methodology, particularly
interpretative phenomenological analysis (IPA) can be effective in exposing the lived experiences of coping as a dynamic and flexible process, particularly from the spouse.

A selection of studies exploring the experiences of degenerative disease have adopted qualitative methodology. Williamson, Simpson and Murray (2008) explored the experiences of individuals living with a partner with PD and their associated psychotic symptoms. Participants emphasised the loss of identity to the illness, as the disease contributed to the ‘deterioration of the person as you’ve always known them’. Bramley and Eatough (2005) addressed the experience of one individual living with PD via an interpretative phenomenological analysis methodology. The dynamic and fluctuating nature of living with PD is exemplified within this study, and demonstrates the complexity of living with a neurodegenerative disease alongside retaining a sense of self and autonomy. As a result, a dynamic methodology, such as IPA, is able to facilitate the understanding of dynamic experiences and thoughts associated with a neurodegenerative condition like PD.

2.11 Study aims

The project will aim to identify and analyse the experiences of spouses of individuals who attend a Parkinson’s disease support group via an IPA methodology. This will include understanding changes identified by the spouse in relation to individual with PD, including how attending the group has led to changes in the spouses’ well-being and daily activity.
3. **Methods**

3.1 **Introduction**

The current study was designed to collect data from spouses of individuals with PD, who attend a voice-specific PD support group. The aim of the study’s design was to explore the spouses’ perspectives of how the group has directly affected their daily life and relationship.

A qualitative methodology was adopted for the study in order to closely examine and investigate the reality of the participant’s thoughts, and create a rich description of the phenomenon in question (Hogan, Dolan and Donnelly, 2011). An exploration into the social worlds elicits a better understanding of their interpretations of the personal relationships with the support group (Smith, 2008).

3.2 **Approach**

The use of an interpretative phenomenological analysis (IPA) approach was specifically used to achieve an in-depth analysis of the data. The aim of IPA is to question how individuals can make sense and clarify their personal world, and provides an insight into how individuals assign meanings to these events (Frost, 2011; Smith, 2004).

In the context of this study, IPA is an appropriate methodology to uncover the interpretations of spouses in relation to the support group, and their personal experiences from it. In addition, IPA has been suited to exploring topics within health, in particular with PD, as it allows the perception of a disease to be uncovered from the perspective of the individual and their family members (Smith and Eatough, 2007; Bramley and Eatough, 2005).

IPA is theoretically underpinned by phenomenological, hermeneutic and idiographic philosophy; these shape the process of IPA and its underlying theory. Phenomenology is the
study of experiences within a cultural context, and is used to extract the ‘insider perspective’ of an individual’s experience (VanScoy and Evenstad, 2015). Under the umbrella term of ‘phenomenology’ lies hermeneutics and idiography. Hermeneutics refers to the philosophy of interpretation; in the case of phenomenology, hermeneutics is double sided, as the researcher interprets the interpretations of the participants (Smith and Eatough, 2007). Idiography relates to a focus on individual and experience, often in the form of a case study (VanScoy and Evenstad, 2015).

3.3 Design

The data was collected using a semi-structured interview design. The interviews were guided using a semi-structured interview schedule (Appendix 7.1). The design was selected to elicit rich and detailed personal accounts from participants, and aid in uncovering the lived experiences of spouses. The researcher has a role in establishing rapport with participants, and avoiding directive and structured interviewing (Taylor, Bogdan and DeVault, 2016). The use of prompts was used alongside open-ended questions, in order to frame questions more explicitly for the participants (Smith and Osborn, 2008).

3.4 Sample

The sample consisted of three spouses of individuals with PD. The individuals with PD all attended a Parkinson’s UK support group targeted at voice loudness for over three months. Participants were given pseudonyms (Table 1), in order to maintain confidentiality. A small sample of participants was considered appropriate for this study, due to the detailed analysis involved.
The method of sampling used was purposive. This refers to the selection of participants because of particular features they possess, enabling a detailed exploration of their experiences to be achieved via analysis (Robinson, 2014). Smith and Osborn (2008) suggest that a sample size of between three and six participants is appropriate for an IPA study.

Table 1: Participant pseudonyms

<table>
<thead>
<tr>
<th>Participant</th>
<th>Involvement in group</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Amelia</td>
<td>Attends group with husband</td>
</tr>
<tr>
<td>2 – Karen</td>
<td>Does not attend group</td>
</tr>
<tr>
<td>3 – Joanne</td>
<td>Does not attend group</td>
</tr>
</tbody>
</table>

3.5 Apparatus/materials

Each participant was given an information sheet prior to the start of the interview (Appendix 7.2), which outlined the study’s purpose and interview procedure. A consent form (Appendix 7.3) was also provided; this was required to be signed and dated by the participation before the interview commenced. Two consent forms were signed and dated: one given to the participant as reference of their involvement, and one kept by the researcher.

As discussed, a semi-structured interview schedule (Appendix 7.1) was utilised to guide the content of the interviews; this is predominantly the exemplar method of data collection for IPA studies (Smith, 2011). The use of open ended questions was selected to establish a rapport between participant and researcher, whilst the researcher had freedom to probe areas of interest, and respond accordingly to the interests and concerns of the participant (Smith and Osborn, 2008).

The interview began with a discussion of how long the group has been running, the overview and aims of the group. This led on to their reasons of attending the group, as well as benefits they have gained from it. More emotionally difficulty topics related to PD diagnosis
and the subsequent changes of the group were left until later in the interview; this ensured a rapport could be built within the first section of the interview, before targeting more emotionally challenging topics (Smith and Osborn, 2008).

All interviews were audio recorded using a Zoom Handy Recorder H2. Audio recordings were stored onto a password protected computer after the interview to maintain confidentiality. The recordings were subsequently transcribed verbatim into a Microsoft Word document. Transcript symbols adopted from Jefferson’s (2004) framework were included to illustrate domains of the interview (Appendix 7.4)

### 2.6 Procedure

The first step in obtaining participants for the study was to contact the support group’s development manager, who was responsible for creating and overseeing the group to establish initial interest for conducting a research via a face-to-face discussion. The discussion explained the area of interest for research, and a query as to whether the study would be appropriate for the group.

The potential participants were approached within a support group meeting to establish interest in topic. Subsequently, participants were contacted formally via email once contact details were shared and ethical approval was granted. Convenient dates and times for the interviews were confirmed via email. One interview took place within the support group venue, whilst the other two took place within the university premises.

### 2.7 Analysis

Following the transcription, the data was analysed using the stages of IPA (Table 2). In order to adopt the principles of IPA, the transcripts were read several times before analysis, to
ensure the participant was the focus of the analysis (Smith et al, 2009). Each transcript was analysed separately after all interviews were transcribed. In reflection of typical idiographic IPA studies (Bramley and Eatough, 2005; Caap-Ahlgren and Dehlin, 2001), close examination of each participant’s personal account is achieved in turn before cross-analysis.

Table 2: The stages of IPA (adapted from Smith and Osborn, 2008)

<table>
<thead>
<tr>
<th>Stage</th>
<th>Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>Read the transcripts four times to familiarise with the text. Note interesting or significant concepts from the participant in the left hand margin in relation to the research aim.</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Return to the beginning of the transcript. Identify and record emerging theme titles in the form of concise phrases in the right hand margin (often the words of the participations to ensure authenticity of analysis).</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Cluster themes identified from Stage 2. List emergent themes in a table and identify connections between them (Appendices 7.11, 7.13 and 7.15) Create superordinate themes from some themes clustering together Subordinate themes may also be generated from this stage</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Produce a table of themes to identify superordinate and subordinate themes Use of verbatim quotes and specific line numbers can be used to support the themes Compare themes over interviews to investigate whether the shared experiences are common across participants.</td>
</tr>
</tbody>
</table>
2.8 Ethical considerations

Ethical consent was gained from the Department of Healthcare and Food Ethics Panel at Cardiff Metropolitan University (Appendix 7.7). Prior to ethical approval being granted, a letter from a national PD charity was required to confirm their support (Appendix 7.5).

The participant’s consent to participate in the study was documented via a written consent form (Appendix 7.3) prior to the interviews. Participants were informed of the right to withdraw, and the voluntary nature of their involvement in the study. Participants were informed of the confidential nature of the project, and that reference to them within the project would be made anonymous. This was included in a participant information form (Appendix 7.2). Locations and names of specific people were omitted from transcriptions, in order to maintain confidentiality and prevent identification of individuals involved. Transcriptions were sent to all participations prior to analysis. This ensured that they had the option to amend or remove any comments from the transcripts.

Potential risks were identified prior to the interview. The topic of PD is potentially upsetting in its nature, and the discussion within the interview could evoke strong emotional responses from the participants. A face-to-face interview allowed the researcher to gauge feelings of distress and react appropriately to this; the interview could be stopped if needed.
4. Results

4.1 Introduction

During the semi-structured interviews, the three participants discussed topics associated with daily life changes as a result of attending the PD voice support group, the benefits gained from their spouses attending a support group. Their experiences of the group in terms of the impact of social participation, as well as considering the support gained from the group were also explored.

To aid differentiation between the spouses and the PWPD, the three participants, who are all women and married to the male PWPD, are hereafter referred to as ‘wives’, and the PWPD referred to as ‘husbands’ within this section.

The three participants’ pseudonyms, as well as their direct group involvement is detailed below:

**Table 3: Participant Information**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Involvement in group</th>
<th>Relationship to PWPD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amelia</td>
<td>F</td>
<td>Attends group</td>
<td>Wife</td>
</tr>
<tr>
<td>Karen</td>
<td>F</td>
<td>Does not attend group</td>
<td>Wife</td>
</tr>
<tr>
<td>Joanne</td>
<td>F</td>
<td>Does not attend group</td>
<td>Wife</td>
</tr>
</tbody>
</table>

Experiences from the participants related to issues explored have been collated into main themes, hereafter referred to as superordinate themes. Analysis of each interview uncovered the superordinate themes:
1. Burden
2. Types of comparison
3. Catalyst for change
4. Facing inevitability positively
5. Mutual trust and friendship
6. Dependence

Under each superordinate themes were subordinate themes, which were evident in some or all of the interviews. The results from these are described and written in a narrative form. Salient points are considered within a commentary. The superordinate themes are outlined in bold, and the subordinate themes are discussed alongside.

The three participants are referred to by pseudonyms (see Table 1 in Methods section). When verbatim quotations are used in-text, the participant’s initial and corresponding line number is recorded. Each of the six superordinate themes will be discussed below.

The superordinate and subordinate themes uncovered within this study have been colour-coded in text; these colours correspond to those used in Appendices 7.12, 7.14 and 7.16.
Table 4: Master table of superordinate and subordinate themes with line numbers corresponding to verbatim quotations

<table>
<thead>
<tr>
<th>Superordinate (bold) and subordinate themes</th>
<th>Line numbers corresponding to verbatim quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Burden</strong></td>
<td></td>
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<tr>
<td>Reduced surface burden</td>
<td>324</td>
</tr>
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<td></td>
<td>158-159</td>
</tr>
<tr>
<td>Reduced emotional dependence</td>
<td>254-257</td>
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<td></td>
<td>100-101</td>
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<td></td>
<td>35-36</td>
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<tr>
<td>‘Break’ from PD</td>
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<td></td>
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<td></td>
<td>348-349</td>
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<td></td>
<td>75-77</td>
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<td></td>
<td>95-96</td>
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<tr>
<td>Reduced self-monitoring role</td>
<td>268-275</td>
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<td></td>
<td>110-111</td>
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<td></td>
<td>404-405</td>
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<td>49-50</td>
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<td></td>
<td>183-184</td>
</tr>
<tr>
<td><strong>2. Types of comparison</strong></td>
<td></td>
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<tr>
<td>Comparison of ability</td>
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</tr>
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<td></td>
<td>88-89</td>
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<td></td>
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<tr>
<td>Comparison of participation</td>
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<td></td>
<td>243-244</td>
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<tr>
<td>Self-consciousness</td>
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<td>Comfort from comparison</td>
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<td></td>
<td>80-81</td>
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<tr>
<td>Heterogeneity of PD’s impact</td>
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<td></td>
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<tr>
<td><strong>3. Catalyst for change</strong></td>
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<tr>
<td>Application of techniques in daily life</td>
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</tr>
<tr>
<td>Catalyst for changes in social participation</td>
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<td>291-293</td>
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<tr>
<td>Education</td>
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<td></td>
<td>86-87</td>
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<td></td>
<td>217-219</td>
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<tr>
<td>Adjusted spouse role</td>
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<td></td>
<td>316-317</td>
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<td></td>
<td>111-113</td>
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<tr>
<td><strong>4. Facing inevitability positively</strong></td>
<td></td>
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<tr>
<td>Catalyst for progress</td>
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<td></td>
<td>162</td>
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<td></td>
<td>25-26</td>
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<tr>
<td>Regaining lost identity</td>
<td>109-117</td>
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<td></td>
<td>204-205</td>
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<tr>
<td>Reduced harshness of diagnosis</td>
<td>350-353</td>
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<td></td>
<td>90-91</td>
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<td></td>
<td>229-230</td>
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<tr>
<td>Active role in progress</td>
<td>158-163</td>
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<td></td>
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<td></td>
<td>312-315</td>
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<tr>
<td>Progress in daily life</td>
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<td></td>
<td>306-307</td>
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<td></td>
<td>330-336</td>
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<tr>
<td><strong>5. Mutual trust and friendship</strong></td>
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<tr>
<td>Sharing lived experiences</td>
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<td></td>
<td>98-99</td>
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<tr>
<td>Social participation</td>
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<td>285-286</td>
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<tr>
<td>Camaraderie</td>
<td>122-124</td>
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<td></td>
<td>311-312</td>
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<td></td>
<td>81</td>
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<td></td>
<td>429-430</td>
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<tr>
<td><strong>6. Dependence</strong></td>
<td></td>
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<tr>
<td>Dependence on group’s longevity</td>
<td>353-354</td>
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<tr>
<td>Exercises as ‘cure’</td>
<td>139-140</td>
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<td>362-363</td>
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<td></td>
<td>140-143</td>
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<tr>
<td>Priority in spouses’ life</td>
<td>364-367</td>
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<td>66-67</td>
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<td></td>
<td>280-282</td>
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</tbody>
</table>
4.2 Burden

Within the superordinate theme ‘burden’, subordinate themes included: ‘reduced surface burden’, ‘reduced emotional dependence’, ‘‘break’ from PD’ and ‘reduced self-monitoring role’. It seemed that the group provided a reduction in burden for across all three wives, in terms of more time for their own pursuits and hobbies and as a caregiver, as well as within monitoring their husband’s voice volume.

Amelia expressed the role of the group in being an opportunity for time away from her husband during the week, and for him subsequently to gain more independence. Amelia subsequently justifies potentially not attending the group with her husband:

‘I want him to have some independence (.) Umm, not that I want to go off gallivanting anywhere’ (A, 323-324).

As a wife who attended the group with her husband, the thought of not attending with him was challenging to accept and to put into motion:

‘I’ve got to let him do or try and do (.) everything that he wants to do’ (A, 156-157).

In comparison, Joanne expressed the need for time away as personal time:

‘I just get two more hours out of (.) I go the gym usually’ (J, 158-159).

Karen also explored the daily burden of PD as a wife:

‘as a husband or a wife, you’re perhaps a little bit too close to it sometimes’ (K, 90-91).

This expresses Karen’s need to have times of release from the PD, and potentially for others to take on this role. She marked the opportunity for herself to be removed from her husband’s daily experiences of the disease; whilst she did not attend, providing her with a temporary break from the burden.
The wives all revealed a reduction in a self-monitoring role as a result of their husbands attending the group, in particular within noisy environments and social settings; they expressed that the need for them to verbally monitor their husbands’ voice volume has reduced:

‘We were out on the weekend, that I’m not asking him to speak up as often’ (K, 110-111).

This is reinforced by Joanne:

‘You’re constantly saying you know like “pardon?” Can you repeat that?’ (J, 49-50).

The ability for the husband to be more active in self-monitoring the volume of their voice has shifted the responsibility from the wife, with this being generalised to activities of daily living:

‘Like we went out on Saturday with (.) umm three other couples, umm and he’s not so self-conscious about it’ (A, 237-239)

4.3 Types of comparison


All of the wives demonstrated that the group was a source of comparison for them, in terms of the PWPD and their current ability and participation. This was generally observed a relief for the wives, in order to compare current and future possibilities. Karen felt the group provided her an insight into what other members are able to do within their daily life:

‘it makes us realise, you know, that you can still travel and (things)’. (K, 249-250).
The wives expressed an initial fear that they would be able to foreshadow future difficulties for their husbands:

‘I was afraid that you’d see people really bad, and then you’d get depressed.’ (J, 83-84).

However, this was contrasted with:

‘even if people are bad, they can still keep doing a lot of stuff?’ (J, 86-87),

suggesting a positive aspect to comparison.

The comparison of their husband’s ability to other group members in terms of impairment was common across the three wives, and this was seen as important within the group:

‘it’s being with people, with a similar condition…it allows you to compare, to talk about things’ (K, 88-89).

This common point of discussion was considered salient for the spouses as a type of comparison, allowing information and advice to be shared.

Joanne felt comfort in comparing her husband’s presentation with other group members:

‘He is (.) still you know making his voice heard, above other people, you know? (J, 78-79).

Joanne is able to actively compare presentations of different group members with that of her husband, and is able to notice an objective increase in volume. It suggests that hearing about other members of the group via her husband gives reassurance that active involvement is aiding in living well with the disease.
However, the comparison and commonalities draw from the wives was also contrasted with Amelia’s awareness of differences amongst the members in terms of progress and coping with the disease:

‘I can see how they deal with it and you know how individuals themselves with Parkinson’s deal with it’ (A, 47-48).

This comment was discussed as a form of comfort for her husband in terms of changes in the future, and that observing members who are more impacted in daily life doesn’t necessarily foreshadow his future impairments. It also suggests that Amelia can observe how different people cope differently with the same diagnosis.

4.4  Catalyst for change

Within the superordinate theme ‘catalyst for change’, subordinate themes included: ‘application of techniques in daily life’, ‘catalyst for changes in social participation’, ‘education’ and ‘adjusted role of spouse’.

The wives also expressed strong roles in encouraging the application of techniques learnt within the group into daily living, and felt that the exercises within the group could be applied in the home environment:

‘and it’s something you know we can quite easily do at home’ (K, 373).

Karen felt that she possessed a strong role in applying the group’s aims into daily activities, to ensure progress.

All three wives recognised the group as enabling change and progress to occur; the use of the word ‘progress’ were used without hesitation across all three to describe the essence of the group. Amelia particularly felt that the group was the catalyst for progression, suggesting a shift of attitude towards the disease:
‘we know from coming here that it’s not (downhill) because there is progression’ (A, 351-352).

Progression was viewed as not solely voice-related progression, but also across activity and participation levels.

The wives felt the group was a catalyst for active change, and that attending it was leading to positive change in daily life. Karen felt that doing anything was better than preparing for the inevitable decline:

‘we’re actually doing something’ (K, 158).

The role of the spouse was identified as key in activating change and achieving progress. Joanne also felt that the group was an opportunity to attempt change at this stage, as:

‘it does get him out of the house…and not sitting at home being miserable’ (J, 36-37).

In contrast, some denial of improvement was presented by Joanne, who felt that the group purely served as maintaining what her husband had now:

‘certainly maintain (.) the sort of speaking ability…I don’t know whether it would actually improve what they’ve got’ (J, 23-25).

The wives felt that the group was catalyst for participating in other social groups and activities:

‘keeping his voice up, it’s umm given him the confidence to go into (.) this choir’ (K, 298-299).

In addition, Karen explored the idea that her husband is now considered to be ‘needed’ within these social activities, which accompanies the primary purpose of improving his voice:

‘this choir, he is needed there as well’ (K, 299-300).
4.5 Facing inevitability positively


All three wives exhibited a positive attitude towards the progression of the disease, and felt that the group was key for helping with this adjustment. They felt that the group was a catalyst for progress, in terms of voice use and participation.

It was acknowledged that the presence of PD altered life dramatically: both Amelia and Karen felt that PD:

‘changes your life’ (A: 132; K, 190).

However, Karen acknowledged that the group aided in viewing the change as positive:

‘it’s not life-threatening, it’s life changing’ (K, 190).

Karen was able to identify the need to adjust daily life, with the group aiding in this transition. This was reinforced by Joanne, who acknowledged the group aided in adjusting to inevitable changes:

‘I think it’s just the hope maybe? The hope that it will sort of stop things getting worse or slow down things’ (J, 261-262).

Amelia felt that the group was a catalyst for regaining her husband’s lost identity as a result of the disease:

‘There’s a glimmer of the [husband] that I used to know’. (A, 110).

It indicates a small indication of hope for future years, and a reassurance for the wife that progress can be achieved. It indicates that the group has aided in re-igniting the stolen identity of her husband within its safe environment.
The harshness of the diagnosis was also discussed, in terms of the role of the group in addressing it. Karen felt that by not attending the group herself, she could have time away from the diagnosis and its implications, feeling:

‘a little bit too close to it sometimes’ (K, 91).

It demonstrates, despite a positive adjustment to coping with the disease on a daily life, time away from the PWPD and the disease gives the wife

4.6 Mutual trust and friendship

Within the superordinate theme ‘mutual trust and friendship’, subordinate themes included: ‘sharing lived experiences’, ‘group support’, ‘relaxed atmosphere’ and ‘camaraderie for PWPD’.

All three women discussed the group as a place for their husbands to share experiences of both PD and non-PD related issues, as well as discuss hobbies and interests openly; they all valued this as salient for living well with PD. The wives felt that the common group of PD united the members, and ensured non-judgement from all:

‘he’s with people who are (.) in the same position as he is’ (A, 19-20).

Discussion of PD-related difficulties was also raised:

‘you can share experiences of the (.) Parkinson’s, you know like mobility, balance’ (K, 433-434).

In comparison, Karen felt that her not attending the group retained her husband’s identity, emphasising the need for her husband to have his own social support away from her.

‘I feel it’s his space, it’s his identity, it’s his group’ (K, 348-349)
The value of the group in terms of offering support for the wives was discussed. Amelia was the only participant who attended with her husband, and she discussed the non-judgemental and group support she experiences from attending the group:

‘although the medical side of it is you know very good (.) it (.) it doesn’t help with the day to day dealing with it (.) but attending this group does because I see and talk to others’ (A, 44-47)

By attending the group, Amelia is able to gain support from other members of the group, as well as consider its management as shifting towards a holistic consideration of her husband as an individual.

The term ‘camaraderie’ was used by two participants to describe the group’s members and its ethos. Both emphasised the group’s mutual interest and friendship at its source. Amelia felt that the group offered a shared interest at its heart that integrated all members:

‘it’s like a camaraderie really’ (A, 122).

Karen also used ‘camaraderie’ to describe the group:

‘the benefit isn’t just the speech, it’s (.) well it’s the camaraderie, umm the meeting of people’. (K, 80-82)

In addition, Amelia felt the group offered a calm and comfortable atmosphere for her and her husband, without judgement:

‘you get to know people know people and in a (.) relaxed atmosphere’ (A, 60-61).

In addition, Amelia felt that the comfortable atmosphere and mutual friendship were responsible for reducing her worries around her husband’s presentation:
‘it’s not regimented, because it’s as much about (.) everything feeling comfortable with each other and umm (.) what’s the word I’m looking for? At ease, you know? (A, 181-184)

4.7 Dependence

Within the superordinate theme ‘dependence’, subordinate themes included: ‘dependence on group’s longevity’ ‘exercises as ‘cure’’ and ‘priority in spouses’ life’.

The wives all expressed their dependence on the group continuing within their daily life for both them and their husbands, and demonstrated hope that the group would continue indefinitely:

‘I’m hoping that they’re going to run forever’ (A, 187-188).

Whilst the wives view the group positively, it also suggests a reliance on it within their lives. Karen also suggests a dependence on the group:

‘what we would do if they stopped it really?’ (K, 438-439).

All participants considered the group as a priority within the week, and commented on how attending it was salient for them and their respective husbands:

‘it has to be something vital for him to have missed’ (J, 282-283).

This was reinforced by Karen, who shared this view of the group:

‘We’d both make sure that he can go to the class’ (K, 66).

The wives also felt that the exercises used within the group were considered to be effective in helping retain voice volume:

‘they seem to have some physical exercises to warm them up’ (J, 14-15).
In addition, Joanne felt that due to the group being run by SLTs, she felt that it was an effective use of targeted intervention:

‘professionals are sort of leading it...it’s obviously something that is worth doing’ (J, 144-145).

The group was described in terms of ‘exercises’ across all three wives, suggesting connotations with physical exercise. Joanne links these two:

‘presumably it’s like vocal exercises as well as (.) physical exercise’ (J, 249-250).

4.8 Summary

Superordinate themes, each with subordinate themes, were converted into a narrative commentary, in which the themes were explained and exemplified with verbatim quotations. All three participants discussed some or all of the subordinate themes within their interviews, with similarities and differences being identified between them. The subsequent discussion chapter will discuss and interpret the results in light of research explored within the literature review.
5. **Discussion**

The aim of this study was to explore the experiences of a PD support group targeted at voice loudness from the perspectives of the PWPD’s spouses via interviews. The use of an IPA methodology helped illuminate and interpret the experiences of the support group from the perspective of the participant, and their subsequent lived phenomena (Smith and Osborn, 2008). This section will discuss the findings of the present study in relation to the relevant literature. The project’s limitations and recommendations for future research, as well as the implications for PD and wider SLT management will be considered.

5.1 **Burden**

The current study highlighted the concept of burden as a theme which is prominent across all three participants, particularly within emotional and physical dependence. Available literature often considers burden as a theme within medical conditions, from both the PWPD and the spouse; often a change in burden is used as measure of the group’s effectiveness, particularly within quantitative studies (Chu et al, 2011).

Research within the effectiveness of support groups with PD is limited, with literature often focusing on aphasia or dementia, or curable medical conditions, particularly breast cancer (Levy, 2011; Hasson-Ohavon et al, 2014). Quantitative research examining dementia support groups has been ambiguous, particularly within demonstrating a significant reduction in burden.

Current literature has demonstrated some ambiguity within the perception of burden amongst spouses, in particular the benefits that a group support may have on reducing burden for the spouse (McLaughlin et al, 2010). The current study was able to clarify this confusion by demonstrating reduced burden from the perceptions of the spouse; the use of IPA methodology was able to support this, highlighting the multi-factorial role of burden from organic
experiences and expose reduced burden as a ‘lived’ experience of the support group. Whilst the study is able to uncover the wives’ lived experiences, the study is limited in terms of measuring change in burden, therefore the study cannot suggest the PD’s effectiveness in terms of relief of burden. Future research adopting scaling methodology within the group context could aid in clarifying this.

Literature surrounding the effectiveness of support groups for PD has often focused on the how the perception of burden changes as a result of group attendance, in both quantitative and qualitative studies. Chu et al’s (2011) exploration of a dementia support group and the effect on the spouse was unable to generate a significant improvement in relieving burden; however, research with a qualitative methodology has exposed this perception of burden within caregiver’s experiences within daily living (Peters et al, 2011).

The current study exposed the reduced role of the spouse in self-monitoring their husband’s voice within social situations; the lack of an ability for the PWPD to monitor their voice loudness is specific to PD (Holmes et al, 2000; Constantineescu et al, 2009; Theodoras, 2011). The findings of the study indicate the group’s effectiveness in addressing voice loudness from a functional perspective, experienced by the spouses. This is mirrored by LSVT’s purpose in address vocal and phonatory effort from an impairment-based model, which is accompanied by a strong evidence base (Ramig et al, 2001; NICE, 2006; Sapir et al, 2007); however, there remains an absence of research which suggests its crossover into functional communication.

Literature exists that supports the feasibility of LSVT principles applied within a group context (Searl et al, 2011); the present study illuminates and further extends the potential for voice specific support groups from a holistic perspective.

Current evidence is limited in examining support groups specific to voice management within PD; therefore, this study is limited in its ability to make clear links with available literature that mirrors the group’s aims and outcomes.
Future research exploring the efficacy of support groups that address vocal effort within PD would be beneficial in considering its place within SLT voice management within PD, alongside conventional programmes such as LSVT, that possess a strong evidence base (Ramig et al, 2001; Sapir et al, 2007).

5.2 Comparison and sharing experiences

The need of support groups for sources of comparison and sharing experiences was salient for the spouses, including aiding in the adjustment of life, regaining their spouses’ perceived lost identity and gaining a sense of hope. This had a direct effect on their daily progress, and within the holistic management of their husband.

The present study has demonstrated that the group is often a source of comparison for spouses, in terms of the levels of activity and participation that group, as well as giving group members an insight into how others cope with the disease’s progression. This need to compare levels of function is reinforced by the current literature regarding the effectiveness of group supports, in terms of disease-specific information. A need for information specific to the condition was considered salient within the dementia literature for the group members (O’Connell et al, 2014), in order to share present experiences and advice. This study’s findings, alongside emerging literature (Smith and Shaw, 2017) demonstrate the desire of spouses to share information, enabling progress within PD and non-PD related entities.

The study’s findings support the current evidence within other progressive diseases that support groups are suitable environments for individuals to draw comparisons and to aid their individual management of PD within their valued familial relationships.

As the group is only able to accommodate for PWPD who have fairly intact mobility, spouses of individuals with mild-moderate PD were interviewed. AS a result, the study is limited in considering the effects of voice support groups in individuals in more advanced
stages of the disease. A different perspective of spouse as a ‘caregiver’ may have been highlighted, as well as their perspective of comparing change and participation.

5.3 Mutual support network

The experience of belonging and creating a support network is a common theme within the literature in the experiences of attending support groups. Findings from this study have suggested the importance of support groups from the spouses’ perspective, in terms of the sense of camaraderie it gives, alongside an important support network. This forms similarities with the available literature, which often highlights support networks as a common theme across the individuals’ and spouses’ experiences within PD (Stanley-Hermanns and Engebretson, 2010). The value of companionship, which in this study is organically described as ‘camaraderie’ is reflected within the literature, in which a shared experience of PD is a catalyst for a sense of community (Smith and Shaw, 2017). Whilst this literature often focuses on the change in support network for the individual with the diagnosis, the current study is able to illustrate the experience of support from the spouses’ perspective, further illustrating the ripple effect of a diagnosis on the individual’s closest network and the need to address this within PD management.

Whilst the study has elicited rich lived experiences from its participants, the study is limited within its sampling. Despite adopting a purposive sample, only one of the three wives interviewed attended the group with her husband. As a result, the findings demonstrate that she had a stronger perception of support and friendship than the other two participants. While the study is able to highlight this difference in perceptions well, selecting participants who did all attend with their husband/wife with PD would have created a

Future research could consider the extent of the changes for the spouses in terms of evaluating change in support networks; this could be achieved via a support network analysis,
would be useful in understanding whether a quantitative, measurable change in social networks had occurred as a result of support group attendance. This would support the efficacy of the group, in terms of evaluating its effectiveness in creating change within the spouses’ social networks.

5.4 Catalyst for change

The present study extracted themes relating to the support group being a catalyst for change within the spouses’ social participation, as well as a change in role for the spouse. An adjusted role of a spouse in current literature often is illustrated via the change in terminology; the use of ‘caregiver’ when referring to the spouse is often used when the spouse takes on the primary physical care for the individual and provides increased support in daily activities (Peters et al, 2011). This is supported by this study’s findings, with the spouses acknowledging an emerging change in role.

The theme of concept of the spouse and the PWPD being jointly responsible in the management of PD is illustrated within current research in terms of coping with the disease in daily life (Hasson et al, 2010). The concept of ‘we’ is mirrored within this study’s findings, with the spouse often expressing the effectiveness of the support group in enabling change within their daily lives. The study has also illustrated the means of the support group in allowing the spouses to take active change in their daily management, and how their perception of this has altered since attending the group.

Whilst this study is able to pinpoint ‘change’ as a superordinate theme from the spouses’ perspectives, it is limited in being able to evaluate this change quantitatively. This would have been able to justify and consider the group’s effectiveness. Further research could consider the change in objective voice loudness and support networks via the use of a support network analysis and objective sound pressure levels (Sapir et al, 2007).
5.5  Facing inevitability positively

The ability to cope successfully with the progress of progressive neurological condition is considered salient in living successfully from the spouse’s perspective. Literature within the field of breast cancer has already demonstrated that support groups are places for spouses to help adjust positively to daily living (Levy, 2011), within a comfortable, non-judgemental environment. The current study’s findings reinforce the positive adjustment to daily living in relation to a degenerative condition, in which spouses can feel more positive in living with PD. This indicates the potential scope of support groups within aiding relationships across a range of medical conditions.

This study has considered the experiences of the spouses within the context of a support, in relation to the dynamic and fluctuating process of living positively with a progressive disease like PD; this is a contrast with the current reluctance for previous researchers in addressing IPA methodology due to the unpredictable and fluctuating impact of degenerative neurological diseases (Audulv, Packer and Versnel, 2014).

The current study demonstrated themes of a positive attitude towards the progression of the disease, including regaining a lost identity, progressing within daily life, as well as emphasising the role of spouse within this. The loss of identity of both the PWPD and the spouse is discussed within the literature, in particular the role of the support group in addressing this. Williamson, Simpson and Murray’s (2008) study considers the loss of identity from the caregiver’s perspective, suggesting that the presence of the disease causes a deterioration of the individual’s personality and identity. The reflection of the loss of identity is identified by the current study’s spouses, with the support group acting as the catalyst in regaining their husband’s lost identity as a result of the PD, resulting in a feeling of hope for the progression of
the disease. This suggests a possibility of effectiveness in support groups within the wider management of PD.

The idea of identifying balance between the disease and daily living is also a theme which is reflected within the available literature and within this study’s findings. Atwood et al (2005)’s experiences of living with PD draw similarities with these study’s findings, in which the spouse has a joint responsibility with the PWPD to retain self-identity and co-manage the disease and living a happy life.

It is important to consider these experiences as a snapshot taken at the time of interview, and that these will change and fluctuate depending on individual lived experience; a positive perception of living with PD at this point make fluctuate and become more negative as associated difficulties arise as the disease progresses. In addition, the role of the support group for the spouse at this time may be effective, but may become less appropriate as the disease progresses.

5.6 Recommendations for future research

This study has been effective in identifying and discussing salient themes related to the experiences of a support group specific to voice rehabilitation. As a result, it acts as base to signpost for further studies that explore its effective in terms of voice loudness and changes in burden and support networks.

Whilst this study has identified a reduction in self-monitoring, further research could consider its effectiveness within PD voice management, in terms of changes in voice loudness, as well as associated gains in participation and activities of daily living. Its effectiveness in leading to a crossover of voice loudness into daily life could also be evaluated. In addition, it could also be evaluated in its role alongside LSVT and other conventional voice management options available.
Future research could directly compare the experiences of spouses who do attend the group with their spouse with PD, compared to those who don’t. This would help understand whether direct attendance has greater positive benefits, or whether similar themes are generated regardless.

A further examination of each theme extracted from this study would help better understand each overarching theme in more detailed. Future IPA-based studies with an ideographical focus would help clarify the individual’s experience of the group in relation to the themes generated from this study. Case study based research would help illuminate the experience of a spouse as an individual. This would benefit the heterogeneity and fluctuating nature of a progressive neurological disease from the spouse’s perspective.

Further studies that adopt a mixed methodology of quantitative scaling and qualitative interviews would help supplement the uncovered experiences with measures of change; this would help validate the emerging research into the effectiveness of support groups within PD for both PWPD and their spouses.

5.7 Implications of research

This research has illuminated the impact of the spouse on a PD diagnosis, as well as the potential positive implications of attending a support group. It has highlighted that the daily living and challenges faced by PWPD are directly experienced by the spouse, as they cope positively with the future progression of the disease. Whilst previous research identifies the themes from the PWPD’s perspective primarily, a focus on the spouse would help understand better the ripple effect of the disease’s impact, as well as consider the possible options available to them in terms of group support and voice management.

In addition, the research has contributed to the limited qualitative research exploring the experiences of individuals with chronic neurodegenerative diseases; as a dynamic and
fluctuating process of adjustment, the methodology and interviewing allowed the researcher to follow and be led by the changes in perception and the process of adjustment.

In relation to current frameworks considering the holistic management of aphasia and Huntingdon’s disease (Kagan, 2011; Power, Anderson and Togher, 2013), a consideration of the spouses’ experience of the disease and the support group has demonstrated the gap in considering a framework for PD. This current study has potential implications as a catalyst for further exploration into measuring participation and activity specific to PD, and measuring its outcome.

5.8 Conclusion

The aim of this study was to explore the experiences of a PD voice support group from the spouse’s perspective. In collaboration with the current evidence within this field, it helps illuminate consider the current management of disordered phonation within PD, as well as the role of the spouse in its wider management. As the first evidence available that considers the spouses’ perspective of a PD support group targeting voice loudness, this study has aided the future consideration of research within voice-specific support groups for PD and the subsequent lived experiences of the people involved with it.

Future research could consider the further exploration of the themes generated from this study, as well as appreciate the individual experience of PD and its progression, as well as the role of support groups in aiding the PWPD and the spouse.
6. **References**


7. Appendices

7.1 Interview schedule

Section 1: General greetings and explanation of process

- How long has your (husband/wife) been attending this group?
- Can you give me a brief overview of the group?
  - Activities
  - What is the aim of the group? Why do you both/spouse attend?
- What encouraged you to start attending the group?
- Prompts: worthwhile? Enjoyable for (husband/wife)?
- When was your (husband/wife) diagnosed with Parkinson’s disease?
- How did you feel when you heard that?
  - Prompt: shock, feeling of burden

Section 2: Break from routine

- How often do you attend Parkinson’s related activities?
- What are the key things that motivate you to attend the group?
- What about your (husband/wife)?
- Do you feel there are benefits for yourself? What sorts of benefits? …What else?
- What has the group allowed you to do that wasn’t there before?
  - Prompts: relief

Section 3: Experiences of attending a group

- How has the group impacted on yourself and (insert name)’s daily life?
- Have you made any friends as a result of joining the group? Who?
  - Tell me more about them…
- What else?
Reference Number: 9592

Title of Project: The spouses’ experiences of a Parkinson’s disease support group: An IPA study.

Information Sheet for participants

My name is Kate Goulding. I am a final year speech and language therapy student. For my dissertation I am really interested in finding out about your experiences as a spouse of someone with Parkinson’s disease. The study involves you, as a volunteer, to take part in it. Taking part in the study, however, is entirely voluntary.

Background

The study will help understand the experiences of husbands and wives (spouses) of individuals who attend a Parkinson’s disease support group.

The study will be based on information gathered from spouses via detailed interviews.

Are there any benefits from taking part?

Giving your experiences on the support group will help to understand the impact that a support group for Parkinson’s disease has on its members and the people most close to them.

Participation in research project

What will happen if you agree to take part?

If you agree to take part in the study, the following things will happen:

- You will take part in an interview with myself. The length of the interview will be between 30-45 minutes, and will take place during a support group session. The interview will be audio recorded.

The interview is an opportunity for you to share your experiences of the support group as a spouse, and is intended to be a relaxed and informal experience.

Why have you been asked to participate in this study?
You have been invited to take part in this study, as it will be a great opportunity to understand the impact that the group has on you as a spouse of its member, and how the group has resulted in changes in your daily life and activity in society for both you and your spouse.

Note: only spouses (husbands and wives) of individuals who attend the Parkinson’s disease support group will be eligible to take part in the study.

**Are they any risks?**

We do not think there any significant risks to you participating in this study. However, there is a mild risk that the topic may be upsetting or cause distress. If this is the case, please say if you would like to stop, and we can reconvene and finish the interview at a later date or just stop it altogether.

**What happens to the results?**

The audio recording of the interview will be transcribed. Any specific names, places etc. will be changed so the study remains confidential. The transcription of the interview will be analysed, and findings included in the final project will be written up. Quotes may be included within the paper.

All recordings and transcripts of the interview will be stored securely on a password protected computer during the writing up of the project, so all information can be kept confidential. This includes your personal details on the consent form. Nothing can be traced back to you and all information is completely anonymous.

After the final Exam Board, all recordings and transcripts will be destroyed.

**What happens next?**

Within this pack, you will find a consent form. Filling this in will give consent for you to be interviewed and therefore involved in the project. Your consent form will be retained for a period of time by the university according to the university guidelines and kept in a locked and secure cabinet.

**Further information**

If you have any questions about the research or how I intend to conduct the study, please contact me via my supervisor – her details are below.

**Contact details**

Project supervisor: Francesca Cooper, Senior Lecturer in Speech and Language Therapy at [fcooper@cardiffmet.ac.uk](mailto:fcooper@cardiffmet.ac.uk).
PARTICIPANT CONSENT FORM

Reference Number: 9592

Participant name or Study ID Number:

Title of Project: The spouses’ experiences of a Parkinson’s disease support group: An IPA study.

Name of Researcher:

The deadline from withdrawing your participation in this study is Friday 16th February 2018.

Participant to complete this section: Please initial each box.

1. I confirm that I have read and understand the information sheet 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.

3. I agree to take part in the above study.
The following statements could also be included on the consent form if appropriate:

1. I agree to the interview being audio recorded

2. I agree to the use of anonymised quotes in publications

_______________________________________   ___________________
Signature of Participant

_______________________________________  ___________________
Name of person taking consent   Date

____________________________________
Signature of person taking consent

When completed, a copy will be given to the participant, and one will be kept in the research's site file.
7.4 Transcription notation

Adapted from Jefferson (2004):

<table>
<thead>
<tr>
<th>Symbol</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>(.)</td>
<td>Micro pause – notable pause of no significant length</td>
</tr>
<tr>
<td>(2)</td>
<td>Number inside bracket – timed pause</td>
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<tr>
<td>()</td>
<td>Information that breaches confidentiality – replaced with non-verbatim summary</td>
</tr>
<tr>
<td>_</td>
<td>Emphasis</td>
</tr>
</tbody>
</table>
3 November 2017

To whom it may concern,

RE: [Redacted] support of the project ‘The spouses experience of a Parkinson’s voice support group’.

I am writing to indicate the support [Redacted] for the above project which aims to establish how people affected by Parkinson’s feel about being part of the group in [Redacted].

Establishing the impact of a local support group will be valuable both to the attendees of the group and to the family members.

We wish the student all the best with their research activities.

Yours sincerely,
7.6 Completed ethics application form

When undertaking a research or enterprise project, Cardiff Met staff and students are obliged to complete this form in order that the ethics implications of that project may be considered.

If the project requires ethics approval from an external agency (e.g., NHS), you will not need to seek additional ethics approval from Cardiff Met. You should however complete Part One of this form and attach a copy of your ethics letter(s) of approval in order that your School has a record of the project.

The document Ethics application guidance notes will help you complete this form. It is available from the Cardiff Met website. The School or Unit in which you are based may also have produced some guidance documents, please consult your supervisor or School Ethics Coordinator.

Once you have completed the form, sign the declaration and forward to the appropriate person(s) in your School or Unit.

**PLEASE NOTE:**
Participant recruitment or data collection MUST NOT commence until ethics approval has been obtained.

**PART ONE**

| Name of applicant: | [Redacted] |
| Supervisor (if student project): | [Redacted] |
| School / Unit: | Health Sciences |
| Student number (if applicable): | 20059800 |
| Programme enrolled on (if applicable): | BSc (Hons) Speech and Language Therapy |
| Project Title: | The spouses’ experiences of a Parkinson’s disease support group: An IPA study. |
| Expected start date of data collection: | End of November |
| Approximate duration of data collection: | 2 months |
| Funding Body (if applicable): | Click here to enter text. |
| Other researcher(s) working on the project: | |
| Will the study involve NHS patients or staff? | If yes, attach a copy of your NHS application to this form |
| Will the study involve human samples and/or human cell lines? | No |

Does your project fall entirely within one of the following categories:
In no more than 150 words, give a non-technical summary of the project

The project will aim to identify and analyse the experiences of spouses of individuals who attend a Parkinson’s disease support group. This will include identifying noted changes about the individual’s well-being and daily activity as a result of their attendance, and how this has influenced the well-being of the spouse.

Whilst the communicative dynamics between an individual and their spouse have been explored within the field of aphasia, a gap in research exists within Parkinson’s disease. As the second most common neurodegenerative condition in the United Kingdom (Parkinson’s UK, 2009), research is needed to explore themes relating to the spouses’ experiences of support groups. This will reinforce and provide information about the effect of a degenerative disease on close family members.

It will be beneficial to explore the impact of group attending within the area of progressive neurological disorders, particularly Parkinson’s disease, including perceptions of ‘burden’ and ‘lack of support’ for spouses.

DECLARATION:
I confirm that this project conforms with the Cardiff Met Research Governance Framework

I confirm that I will abide by the Cardiff Met requirements regarding confidentiality and anonymity when conducting this project.

STUDENTS: I confirm that I will not disclose any information about this project without the prior approval of my supervisor.

Signature of the applicant: [Redacted]
Date: 19.10.17

FOR STUDENT PROJECTS ONLY
Name of supervisor: [Redacted]
Date: [Redacted]
A RESEARCH DESIGN

A1 Will you be using an approved protocol in your project? No

A2 If yes, please state the name and code of the approved protocol to be used:
Click here to enter text.

A3 Describe the research design to be used in your project

The project will use an interpretative phenomenological analysis (IPA) design, in order to explore the experiences of spouses and establish themes in detail. Participants will be interviewed using a semi-structured interview schedule (see separate sheet for questions).

It is unlikely that the approach of the project will change as research develops. The involvement of participants will be necessary for the project, as the aim of the project is to interpret and explore the lived experiences of spouses. This will only be possible via the use of participants’ involvement in the project.

The interviewing will take place at the public meeting place of the support group. It will be possible for the interview to take place in a quiet room away from the group. The interview is likely to take between 30-45 minutes, and only one session per

---

1 An Approved Protocol is one which has been approved by Cardiff Met to be used under supervision of designated members of staff; a list of approved protocols can be found on the Cardiff Met website here
A 4 Will the project involve deceptive or covert research?  
No

A 5 If yes, give a rationale for the use of deceptive or covert research

Click here to enter text.

A 6 Will the project have security sensitive implications?  
No

A 7 If yes, please explain what they are and the measures that are proposed to address them

Click here to enter text.

B PREVIOUS EXPERIENCE

B 1 What previous experience of research involving human participants relevant to this project do you have?

In year 2 I did an IPA study in psychology.

B 2 Student project only

What previous experience of research involving human participants relevant to this project does your supervisor have?

Supervision of numerous undergraduate projects.
<table>
<thead>
<tr>
<th>C POTENTIAL RISKS</th>
</tr>
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<tbody>
<tr>
<td>C1 What potential risks do you foresee?</td>
</tr>
<tr>
<td>There is a mild risk of upset due to the topic area.</td>
</tr>
<tr>
<td>C2 How will you deal with the potential risks?</td>
</tr>
<tr>
<td>If the participant becomes upset, they will have the option of stopping the interview and rearranging the interview for a later time, if they feel. Or withdrawing altogether.</td>
</tr>
</tbody>
</table>

When submitting your application you **MUST** attach a copy of the following:
- All information sheets
- Consent/assent form(s)

An exemplar information sheet and participant consent form are available from the Research section of the Cardiff Met website.
Wellcome Trust

BSc (Hons) Speech & Language Therapy
Cardiff School of Health Sciences

Dear Applicant

Re: Application for Ethical Approval: The spouses' experiences of a Parkinson's disease support group: An IPA study.

Project Reference Number: 9592

Your ethics application, as shown above, was considered by the Health Care and Food Ethics Panel on 15/11/2017.

I am pleased to inform you that your application for ethical approval was APPROVED.

Minor issues may still need addressing before you commence any work — if so these will be listed below.

N/A

Where changes to the information sheet, consent form and/or procedures are deemed necessary you must submit revised versions to the relevant ethics inbox. If you are a student — your supervisor must do this on your behalf.

Note: Failure to comply with any issues listed above will nullify this approval.

Standard Conditions of Approval

1. Your Ethics Application has been given a Project Reference number as above. This MUST be quoted on all documentation relating to the project (E.g. consent forms, information sheets), together with the full project title.

2. All documents must also have the approved University Logo and the Version number in addition to the reference and project title as above

3. A full Risk Assessment must be undertaken for this proposal, as appropriate, and be made available to the Committee if requested.

4. Any changes in connection to the proposal as approved, must be referred to the Panel/Committee for consideration without delay quoting your Project Reference Number. Changes to the proposed project may have ethical implications so must be approved.

5. Any untoward incident which occurs in connection with this proposal must be reported back to the Panel without delay.

6. If your project involves the use of human samples, your approval is given on the condition that you or your supervisor notify the HTA Designated Individual of your intention to work with such material by completing the form entitled "Notification of Intention to Work with Human Samples". The form must be submitted to the PD (Sean Duggan), BEFORE any activity on this project is undertaken.
This approval expires on 15/11/2018. It is your responsibility to reapply / request extension if necessary.

Yours sincerely

[Redacted]

[Redacted]

Chair of Department of Healthcare and Food Ethics Panel
Cardiff School of Health Sciences
Llandaff Campus
Western Avenue, Cardiff CF5 2YB
Tel: 029 2041 3228
E-mail: [Redacted]

PLEASE RETAIN THIS LETTER FOR REFERENCE
Interviewer (I): Ok, er, Thank you for agreeing to be interviewed.
Umm this is going to be a quick interview about umm your experience of your husband attending a Parkinson’s support group.
Umm, so firstly, umm how long have you been attending the group for?
Amelia (A): Since it started.
I: Yeah, when was that?
A: Umm (2) oh last year, not sure when, but we’ve been going for some time.
I: Yeah, ok. So (3) can you kind of give me a brief overview of what you do in the group and what it sort of aims to do?
A: (2) Basically, umm I think it is as it says, LiveLoud, it’s to do with encouraging him, with Parkinson’s, people with Parkinson’s to speak up and speak loud, and (2) practice their voices, if you like. Umm and we do that through discussions umm group discussions but also (.) as a whole. And (2) umm and sort of speech (2) therapy if you like, if you see what I mean, you know sounds (.) and umm (2) and I think (2) for me, that what I like is (.) [my husband] relaxes when he’s here (.) Because he’s with people who are (.) in the same position as he is, he’s not as nervous as he is anywhere else (.) Umm and that helps him to speak. Umm but you know, I know it’s a pilot scheme at the moment (.) to my mind it’s made a big difference to [my husband]. Big difference.
I: Yeah, that’s good. That’s good to know. Umm ( ) ok (2). So you’ve mentioned you noticed differences in ( ) him. Is that to do with his kind of confidence, would you say in speaking?
A: Yes, yes it is (2). But it’s (5) it’s made the difference to his attitude as well I think to Parkinson’s ( .) you know? Umm he’s not so ( .) self-conscious about it. He’s not (3) it encourages him because he can see what other people can do (2) Umm and then realises that he can do the same, he just puts ( .) a bit of effort into it you know? (laughs)
I: Yeah, so obviously for [husband] and he comes to this to help him.

Umm (5) can you tell me a little bit about your perspective of that so as his as his wife (.) have you noticed anything specifically umm is there anything you've kind of taken away from the group?

A: Umm (.) yeah I think it's (.) umm I think it gives me support (2)

Umm (.) because (.) I mean we do go to parties and to cafes, and that's a really sociable thing (.) but (.) coming to the sessions (.) umm I've learnt a lot (.) about what Parkinson's is about (.) umm the different aspects, the different symptoms and also (.) umm how other people cope with them? (.) Umm and that's helped me tremendously to (.) deal with the different things that happen with (.) with you know? And as I say, it gives me (.) more confidence? (.) Because (.) I mean although the (.) medical side of it is you know very good (.) it (.) doesn't help with the day to day dealing with it (.) but attending this group does because I see and talk to others. I can see how they deal with it and you know how individuals themselves with Parkinson's deal with it, but also (.) umm how the carers or wives, partners, deal with it. Umm (.) so yeah I think it's uh really I think I've learnt a lot more actually (.) from coming here than I have from anywhere else (.) for Parkinson's (.) and how to deal with.

I: Yeah in a functional way and social kind of (.) yeah. Ok. (2) Mmm.

Ok, so you mentioned the Parkinson's café, is there anything else that is Parkinson's related that you attend?

A: Umm (.) No, well we attend this but we attend a couple of the cafes (.) Umm (.) and (.) umm fundraising (.) umm (.) things umm like the branches (.) is very proactive (.) In umm fundraising umm (.) but it's also a real (.) umm (.) it's umm, it's not just a social, they're not just a social function, they're friends (.) you know? Because you get to know people and in a (.) relaxed atmosphere (.) umm and once again, it's just gives you the support, but also (.) gives as well.

Umm (.) but it's you know sometimes I'm, sometimes it can be a bit scary because you can see people who have had Parkinson's for a lot...
longer and how it affects them. (I) and it makes you think. (I) oh
if this happens how am I going to cope with that? You know. (I) Umm
and I know that [my husband] also sometimes thinks about that,
because he sometimes mentions it you know? And I just think it
doesn’t necessarily mean it’s going to happen [my husband]. (I)
everybody is different. (I). That’s why I think research and everything
takes so long in Parkinson’s because there are so many different
symptoms and so many aspects generally to it. It’s really difficult to
help everybody, you know?

I: Yeah, yeah definitely. It’s quite complex.

A: It is.

I: Definitely. Umm so what encouraged you to kind of start
attending the group here? What kind of started that off?

A: (2) Umm basically I think it’s the Speech Therapist at [the
hospital]. She umm told us about it, umm and then (I) umm
then [the supervisor] came down and gave a talk (I) at the cafes
about it. Umm and then we were able to discuss it with friends that
we were sat with, and then [the supervisor] said if you’re interested
(I) just give us your name. And in fairness to [my husband], he will (I)
try anything. You know, if he thinks it’s going to help him he’ll try
anything. So I said, do you want me to put your name down? And he
said yes. (I) So we did. So it was basically through the café again. You
know, and [the supervisor] telling us what it was all about and how
it was going to be run. And of course [the lead volunteer] then (I)
giving us a chat as she was (I) running it you know?

I: Ok, yeah. Definitely. Ok. Is there any, has there been a specific
aspect of the group that’s really (I) created a specific change in [your
husband], or as a general thing it has?

A: (I) Umm (2) I think (2) uh I think it’s just general. I think it’s
because (I) umm (2) everybody (I) is so nice, and everybody is so
friendly, [the lead volunteers] do a grand job of (I) you know umm
thinking of thinking up of all these ideas and things to do, you know
and sometimes I think to myself god how do they do it? You know? Umm (.) but (.) it's just like as if you've been on the tour club, you know? Umm and it gives you that sense of (.) belonging (.) to something and having support from others (.) even if it's just the fact that they're there. (.) with you, and trying and doing their best, the same as you are. You know.

I: Yeah, definitely. Umm (.) so (4) hang on a second. Sorry (.) Umm (2) coming away from the group, do you see that attending the group has created has been mirrored in your daily life? Has it kind of created changes in your, in your everyday life? With [your husband].

A: Umm (.) yes I think it has. Because (.) umm, as I say he's more confident than he was. We go out (.) with other people (.) now he is more confident than he used to be umm (.) and also sometimes there's a glimmer of the [husband] that I used to know. You know? Umm he was always very confident, very strong, life and soul of the party. Made me laugh, which is one of the reasons why I married him. Because I wanted some (.) my dad always made me laugh. My childhood was so happy. I wanted to marry somebody else, who could make me laugh and now, with the confidence that comes from attending these things, with [my husband], we (.) I get that (.) that glimmer of the person coming out, or the joking and the (.) you know have er cheerfulness, you know coming out? Which I think really helps him (.). really helps him cope with everything he has to cope with. You know?

I: Definitely.

A: It's like a camaraderie really. Particularly in (.) uh as the majority of the group are men anyway. It's umm making up for the camaraderie that he misses (.). outside, you know?

I: Yeah, he may miss out on now slightly more. Yeah. Ok (2). Have you noticed a change (.) umm from when you did not attend the group to now? Has there been changes (.) kind of from being within
the group and being without the group, if you see what I mean. So kind of like (.)

A: Umm yes I think attending the group’s and umm other things with Parkinson’s umm (.) has basically helped me for a start (.) to accept (.) the fact that Parkinson’s changes your life. Definitely changes your life. Umm and I think (.) if it wasn’t for the support, of this LiveLoud! And the cafes, and the people involved with Parkinson’s, I don’t think I would be coping with it as well. Or [my husband]. As we are, if we didn’t have that support, so I think it yeah, it’s made a huge difference and it makes a huge difference, even when we’re home on our own, because it’s Parkinson’s is always in our mind, and we do do you know practice speech and things like that at home, which again is, is something else we do together. Exercising, taking him out walking. Is something that we do together, so it has made a difference, definitely.

I: Oh good (.) umm (.) ok (2) has there anything that the group has allowed you to do that you couldn’t do before?

A: Me personally?

I: Umm yeah, yeah. Anything that you...

A: (3) I think it’s made me (.) umm (2) more aware of, I think I did too much for [my husband] (.) when we first (.) before we attended these things. Umm because you just tend to, because you know he has difficulty doing things and, you know everything takes him so long (.) umm but coming here and seeing what other people do and (.) that (.) the only thing is (.) the other carers don’t come, so I don’t see it from that point of view, but umm just seeing what the other men for example (.) do and how they manage to do things that, or talk about things that they manage to do, you know, umm and I think that this (.) has helped me to realise that I’ve got to let him do or try and do (.) everything that he wants to do, and if he then says he can’t do it, or I’m having a problem, then I help him, rather than
(.) jumping in beforehand, you know? Because it gives him that little
bit more independence.

I: Uhm. Ok. Yeah (2). So you said you mentioned there’s a
comradeship with the group (.) umm can you tell me a bit more
about that and your kind of friendships that have developed as a
result of the group?

A: Umm (2) well I think (.) I mean, you know, we get on with all of
them, but umm [my husband] and [other group member]
particularly seem to have a link, you know there seems to be a bit
extra uh between them, umm and it’s the same with other people
that we meet in the groups that are organised by Parkinson’s, you
know? Umm and it’s (2) I just think because we, your social life
changes because the people you normally would socialise with, sort
of drift away, umm we don’t, it’s difficult to umm take that on board
when that happens but I don’t resent it, it’s just the way of life.
Things change unfortunately, and uh, but it just (.) makes it (.) easier
to make (.) to change to make the changes in your own lives, that
you have to make. Umm and you know, he really loves coming, he
really looks forward to coming every time we have a meeting. Even
if he’s not feeling 100%, he will still want to come. You know? Which
is great because there aren’t many things at the moment that he
gets that enthusiastic about, you know? And again, I think that’s also
because of the way that [the lead volunteers] run it, because it’s not
regulated, because it’s as much about (.) everything feeling
comfortable with each other and umm (.) what’s the word I’m
looking for? At ease, you know? To do these things or try and do
these things or take part umm but also, although it’s umm (.)
relaxed, it’s very beneficial. To everybody. You know, in different
ways to everybody. Umm (.) and I, you know, I’m hoping that they’re
going to run forever, you know?

I: Umm, so you mentioned that (.) you are the only kind of carer or
spouse that attends the group with [your husband] (.) why is it that
you feel (.) uh why is it that you attend with him?
A: Basically with [my husband]. First of all it was because he wanted me to attend, because he wouldn't feel confident at that time without me being there. But the main reason, or one of the main reasons I attend with him now is because [my husband] has a problem, cognitive issues so if they're discussing something, for example, he wouldn't have remembered what he had to do for this session if I hadn't been here. You know? (cough) and umm if anybody has got any information for example sometimes [another group member] comes with information about other things, or about research and things like that, well [my husband] although he'll be listening and taking it in at the time, if I then ask him what it's about when he comes home he won't be able to tell me. Because he, it just goes. You know? Umm and it's the same when he's talking, he'll uh he knows what he wants to say, but the words sometimes actually don't come, you know? Umm and so really, that's basically why, because if I'm there and he wants to say something I know how to prompt him without actually telling him, because I do it all the time at home, you know? Or I can guess, what it is that he wants to say. So basically, I would say that's the main reason, is his cognitive issues. Other than that, I think he would be ok on his own.

I: He would be fine. Yeah. That's interesting.

A: And I, you know, it'd be interesting, having brought the subject up with [the lead volunteers], the only thing I've said on occasion is you know if you get a lot of people come, and you haven't got enough room, just tell me, and I will go. I wander round and then come back, umm but I haven't actually you know said to him, do you have any objections or do you think it would be better for [my husband] if I wasn't here? but then I haven't also had the opportunity to explain to them why, the main reason why I come with him now. I still come with him, you know?

I: Ok, yeah it's just interesting to see it as a perspective of someone who attends whereas someone doesn't, how they see it.
differently? Yeah, ok. (.) Umm (.) just check, ok loads of time, we’ve
got ten minutes or so. Umm (4) ok (3) so umm (.) I think it’s more
about (.) talking about (.) umm (.) obviously as you attend, it’s kind
of different, as like someone who doesn’t attend, so you’re with him
and you (.) it’s kind of a partnership there, umm (4) sorry, I’m
getting a bit confused with what I need to ask. Umm (7) can you tell
me a bit more about (.) the influence of this group upon your kind of
(1) life outside of the group?

A: (3) The big that comes to mind is that (.) umm (.) as I say, coming
to coming to the group (.) has helped me, I think, to cope with (.) the
difference it makes to our lives and (.) to help [my husband] (.) much
more than I used to be able to help him (. .) umm but it also (.) has
given him extra confidence. if we go out socially with friends, like we
went out on Saturday with (. .) umm three other couples, umm and
he’s not so self-conscious (.) about it (.) umm (.) it’s as if he’s found a
new confidence in him, as you know, well this is me you know so
take it or leave it sort of thing. Umm (.) and he has, you know, made
as (.) [the lead volunteer] has said to do, that if you go out in the
social group, he’s been proactive (.) in sitting between two friends (.)
so that he can hear, he is also deaf, has two hearing aids, so but he
is proactive in not just sitting where everyone says to, he says you
know, can I sit here because it’s easier for me (. .) umm like we did
Saturday, all the men, the four men sat on the one side (.) of the
table and the ladies on the other, so that he could (.) hear (. .) and
ummm (.) take part in what the men were talking about, because
obviously men talk about different things to the women, you know.

But it’s given him the confidence to do that (.) umm and he’s (.) even
where even we’ve moved now, it’s a totally different way of life, on
the new swing (.) the relationship (.) made new swing (.)

Less dependence
on wife (.) burden

change in social

change in self-

change in social

reduced burden
It's made a big difference to him and his attitude to Parkinson's itself, you know? Yes I've got it, and I've got to just make the most of it, you know?

I: Yeah that's interesting (2). I think as well, from your perspective, it seems that you've kind of like (.) umm noticed some things that have helped you, as a result of him attending. Was there anything, can you tell me more about that, those sort of good things that have come out of him attending the group? For you. So not so much for Dave, but for your kind of benefit maybe?

A: Umm (.) yeah (.) umm one of the things like I said is his slightly more independence (.) for him, and I'm not afraid to do that now? I was afraid before (.) umm (.) and for example, if he went out (.) I went, you know? Even if it was only to the local shop for the paper, I used to go with him (.) just in case he lost his balance, just in case he fell (.) umm if he had problems asking for what he wanted when he got there, this sort of thing. Umm (.) but that's one of the things (.) that has changed because I do feel now (.) like I said that I must let him (.) do what he wants to do (.). Umm he's always got his phone, so if he needs me he just rings, umm because my phone's there all the time (.). Umm (.) and it's (.) I think it's made me easier about (.) umm coping with Parkinson's (.) because I've seen how people like the friend I was saying about who can't talk, how his wife deals with it because he's obviously physically quite (.) bad as well (.) umm and (2) it's made me realise really how lucky we are (.) you know the fact that [my husband] is the way he is at the moment (.) and I mean there's lots of ups and downs. He's got a problem with his eyes at the moment. I think we both just feel that, we're lucky that he is as he is, it could be a lot worse, you know? Umm (2) but they I think (2) umm yeah the biggest thing for me is the (.) me actually being able to give him some independence, whereas before I couldn't, before I came here, I just couldn't. And I've seen particularly (.) [another group member] who's not here today, you know the fact that he comes here on his own as he is, and by public transport and goes back and he's absolutely (.) fine, you know? And I think crumbs if he
can do it, then [my husband] will be able to do it. (. ) you know? Umm and I sometimes think I ought to say to [my husband], why don't you try going on your own you know? And see how you get on. But I know that he wouldn't (. ) but if that was the case, then perhaps I could say to [the lead volunteer], look if you give him any instructions of what he's got to do for next time or any (. ) dates or anything, can you email me (. ) you know and let me know. Just really like to know (. ) without him (. ) being there (. ) I would like to ask [the lead volunteer] what she thinks about whether it would be more beneficial for him to come on his own (. ) than it would be with me there all the time (. ). But it's difficult to do that, because I can't get the opportunity to (. ) see her on her own, you know?

I: No, that might be worth...

A: I don't know whether I'm doing the right thing or the wrong thing (. ) you know? I mean so far it has been beneficial definitely for both of us (. ), but I do sometimes think perhaps now it's time for him to come on his own independently on his own (. ) you know, even if I say to him (cough) look [husband], I'll come into town with you (. ) I'll go and do something else, and then I'll come back (. ) to start with, because then I know when he's in here he'll feel safe (. ) you know?

And then gradually then perhaps he'll be able to come independently on his own. But I don't know whether that's the right or the wrong thing to do (. ) So

I: I think, hmm I'm not sure.

A: No it's difficult to know what's right.

I: I suppose you're with him now, so you could try not coming in and seeing if there's a difference, and see how he feels.

A: I mean, I haven't said to him yet, you know would you go on your own? Do you think it would be now to go on your own? Because I don't want him to think that I don't want to come with him. I want him to realise it's because I want him to have some independence.

(.) Umm, not that I want to go off gallivanting anywhere, I just want
him to (.) be as independent as he can be for as long as he can be (.)
you know?

I: You mentioned that (.) [your husband] feels safe. (.) Is that quite a
theme that's...

A: Yeah, absolutely.

I: A kind of network that's safe, would you say?

A: Yes, so I was saying that (.) that's quite (.) perhaps not just a, he feels safe when he's here (.) when he's amongst people who understand what Parkinson's is all about (.) you know? Umm and that's, you know, that's a big thing, because (.) prior to coming here,
he felt very very vulnerable. So much so that you know, we didn't go out as much as we do now (.) umm and he would never have thought of going (.) to a local shop (.) to get something (.) umm because he, when we were in the house, he did fall one day in the street, and people were passing and nobody, nobody came to his assistance at all (.) you know? And so that (.) you know (.) knocked his confidence (.) umm but fortunately, you know as I say he's gaining his confidence (.) more now, he's going to the local shop. It's not that far, I know, but to do it, to go the shop, to get what he wants and come back on his own (.) for him is something that he wouldn't have done if he hadn't started coming here.

I: Yeah, it's nice that even though it is a sort of something degenerative in nature, there's some improvement.

A: Yeah, there's progress.

I: Yeah progress. Which is...

A: Exactly, because you tend to think that when the diagnosis is given it's all going to be downhill (.) but we know from coming here that it's not (.) Because there is progression (.) you know in more ways than one (.) you know. So to me, I think it's one of the best ideas they've ever had.
I: That's great (laughs). That's always good to know. I think, yeah.

Let me just check the time (1). I think we'll wind down now with the last things. Umm (.) yeah. Do you see (.) the group as an important network in your kind of life, your daily life?

A: Yes. No absolutely.

I: Would you say that's. Sorry carry on.

A: Yes because (.) it makes [my husband] do things, like he (.) I need to keep reminding him (.) that this is what you've got to do, you've got to find something to read out or (.) but it makes him (.) more active because he'll go online, and then he'll look for something, and he won't just pick anything, he will go on and (.) he found this (.) poem and (.) he liked that one, so this is the one he decided to print and you know it makes him more active in doing things (.) umm the same with doing any exercise at home or going walking (.) even though because he's in pain so much all the time, he might not want to (.) this gives him the enthusiasm (.) to do as much as he can to help himself.

I: Yeah.

A: So you know it's been really good, as I say it's not just the progression in (.) umm his speech and (.) communication, but also physically and in his general well-being. It's helped in all sorts of ways. Which I don't think we would have got from anywhere else.

I: No that's, that's good to hear. It's good that it's a positive kind of outcome for you.

A: It is.

I: I think we'll leave it there. thank you very much for your experiences.

A: You're welcome.
Karen – Analysed Interview Transcript

Interviewer (I): (2). Ok. Thank you very much for agreeing to be interviewed. Umm this is going to be a sort of a thirty minute forty five minute (.) kind of interview about (your husband) (.) his and your experiences from attending the Parkinson’s support group. Umm so, first of all, how long has (your husband) been attending (.) the group?

Karen (K): I’d say about 18 months, so about 18 months, yeah. And um it was arranged through (the hospital) through a lady called (the SLT), yes so uh.

I: Okie doke. Umm from your experience, can you give a kind of a brief overview of what the group’s about?

K: Umm (.) with Parkinson’s, we found out that the voice can become quieter, and (.) I was concerned about this as was (my husband) because you know I was concerned that people wouldn’t hear him properly? So through (the SLT), she said that there was a group starting called (.) and you know (my husband) was keen to join this group, because if people can’t hear you, you can become a bit excluded from conversations, and as a sociable person, and we didn’t want that. So umm, the main reason was to raise the volume of his voice (.) and to you know, umm this through a group. We do the exercises at home but you’ve got to be very disciplined to do that. When you go into a group, you get new ideas, I thought there’d be new research coming through, and it’s proving to be successful. Yeah.

I: Yeah. Have you found the kind of group (.) uh the group setting more effective than...

K: Most definitely. We were given any exercises by (the SLT) at (the hospital) which you try to do, but you find other things get in the way. Umm you’ve got to be very disciplined in the morning to do the exercises. But of course going to a group like this, you’re having this two hour session which is focused on the volume of your voice. Umm you get new ideas.(My husband), especially some exercises,
he especially enjoys which he finds beneficial, which perhaps later in
the interview I'll explain to you as well, but most definitely, plus
umm in a group situation, you're interacting as well, and the other
thing they do is give a little homework: find a poem, a funny
experience in your life, you know? A chance to relate that as well.
But being in a group, most definitely he's sharing experiences with
other people with Parkinson's, you can compare with yourself. Umm
and he's finding it really reassuring as well. Yes.

I: Yeah, that's really good. Umm (2) so (.) you mentioned that
through your (.) through (The hospital) was how you started
attending the group, umm (2) have you noticed a difference
between him now attending the group and before?

K: Definitely. Yes most definitely, because I was concerned because I
suppose, as a couple we're social, we go out quite a lot, and in
most places these days there's background music, places are noisy.
And I was noticing that people were asking (my husband) to speak
up (.) And I think as a person, I don't think he had a really loud voice,
but with the complication of the Parkinson's, I could find the volume
was quite low? So (.) most definitely now, noticing that people less
and less are saying you know 'speak up' or 'we can't hear you'. So
from that point of view, umm (.) it's had a beneficial effect because,
we were both afraid, as I said, people can't hear you, you start to
become a little bit excluded from the conversation, you know?
They're not hearing you properly, and they might give any answer
just to show they're engaging, but most definitely, his confidence is
improving as well, and I think that less and less when we're out,
people are asking him to (.) speak up. So umm, I think the group
focuses him, he's enthusiastic about the group, and he wants to
improve, so umm, it is helping because you know, a lot of
environments we're in are noisy so, uh, yeah.

I: Definitely. So (3) umm. You mentioned that umm (.) he really
enjoys it, and is it something like a highlight for him?
To be honest it is, and whether we're going on now, you know we'd both make sure that he can go to the class. I've got to be honest, he absolutely loves the class. He comes out of the class beaming, saying how much he's enjoyed it, how lovely the people are. He's making friends in the class, and umm not only that, but we're both retired, you've got to make sure that you have got separate interests and you bring something back to the house? And, you know, either I meet him in town afterwards or he'll come home, and he talks about [group member] and [group member] and is it [lead volunteer] who runs the class? [Lead volunteer] and [lead volunteer] is it? [Lead volunteers,] and he says the students in the class so umm, he is full of enthusiasm, and I think the benefit is not just the speech, but to be in that group situation, umm to see progress, to try different exercises, and he's always enthusiastic about the homework or finding a poem, or a funny story, that he is enthusiastic. He definitely loves going to the class, so the benefit isn't just the speech, it's (...) well it's the camaraderie, umm the meeting of people, you can compare yourself with other people, there's a lot of sharing of experiences as well. Because you know, at this stage, [my husband's] balance wasn't very good, and he was able to (...) talk to the others about balance, and they say that that can change you know over phases, you know, you do go through a phase where your balance isn't very good, so it's not just the speech, it's being with people, with a similar condition to yourself, and it allows you, you know it allows you to compare, to talk about things, you know, as a husband or a wife, you're perhaps a little bit too close to it sometimes, but umm, it gives them a chance to (...). speak to people who have lived in that experience (...) as well. So umm (...) definitely from a speech point of view, but he always comes out of there beaming. So uh, he loves it. Yeah.

Ah good. Umm (...) from (2) your perspective, obviously when (my husband's) at the, he attends the group, is there anything that he group has kind of allowed you to do, that you wouldn't have
been able to? From your experience. Umm (...) rephrase that. Do you feel that there are any benefits yourself for (your husband) attending?
K: Because I'm more relaxed out, because (...) if you're out with someone, and you feel they're being left out, you're out with a group of friends and someone's being left out of the conversation (...).
Umm (...) you're not as relaxed, because you're worried about them and then you're worried that people won't hear them properly because it is a little bit frustrating for people if you can't hear someone. Not only that, I mean (my husband) is 64, I'm 60, umm people's hearing isn't as good as they get older very often, so you've got to allow that factor, but umm they might not be hearing as well, so it's all compounded by that, so it's made me, I've noticed recently. We were out on the weekend, that I'm not asking him to speak up as often. And what I do when I'm out, if I think he's speaking really quietly, I go like that (gesture), so speak up, but I'm finding that I'm doing that less, you know, and I'm giving him a little bit of a nudge to speak up, because he (...) thinks he's speaking loudly, but he's not. So he does think he's speaking loudly, and he's not speaking loudly, and umm (...) you know people are struggling. But you know, sometimes we go out and there's a disco playing and that, and we've all got to shout. I mean, I was hoarse on Sunday from one Saturday night because it was a loud band playing at a party. But (...) it's getting him now to allow for that as well. But most definitely, but if someone can't be heard, or you think that they're not engaged in a conversation, it's really hard to relax you know. Because you care for them, you want them involved, you know and he's got too much as a person to just be sat there. And I don't want that, I want to keep him in the loop, despite the Parkinson's, I want to keep him in the loop. When we go out, so umm (...) I think he had a real lift last week because was (the SLT) there last week? Or was it (the lead volunteer)? But somebody said to him, that he's definitely improved. Yeah, that was a real lift, I was pleased about that. Now, he did go through tests at (the hospital), because (the SLT) was worried at one stage that he was hoarse. I think it was because we
went through doing these exercises like all together. But (the
hospital) looked at his vocal cords, he's had a camera, and they've
looked at it, and they've said his vocal cords are fine. So umm, there
is, there's no reason why he shouldn't, really work at this now and
speak up. Definitely a great effect for me. It's important that he
keeps going I think, because it helps us both relax, but he's now (~)
engaging in conversation, and he did go through in the beginning,
perhaps it's your confidence as well, when people weren't hearing,
and he was maybe not taking part as much, but I wouldn't say that
now. Yeah, it's really great for us.

I: No that's really good. Could you tell me a bit, a bit more about
how the group has impacted on (~) you and (your husband's) kind of
daily life?

K: Umm (2) I mean I said a lot of this before that he can be heard
when he's out. I also think the exercises you know where you've got
to talk about experiences to a group improves your confidence as
well. Because (~) umm (~) you know when you're diagnosed with
Parkinson's, I mean (my husband) is basically a quietly confident
person, but you know it would affect your confidence a little bit,
probably some people a lot. But the fact that, I think, in the group
situation you've got to talk about an experience, you've got to read
a poem, I'm trying to think about other things they do within the
group. Umm read out sentences perhaps or limericks or whatever.

Umm the fact that you're reading this out to a group keeps your
confidence (~) going as well, you know? And you've got to think
haven't you. So umm from that point of view, as a couple, it (~) it's
helping us. And also, we're actually doing something to (~) you know,
not give in to the Parkinson's. It is progressive, we're both realistic
about that, but I am still convinced, if you keep exercising and keep
working (~) at things like you know the level of your voice that you
can help (~) help things along. And the fact that, we're actually doing
something about it, and that he's seen progress now umm, has
impacted on both of us, as a couple. And it is better, you know, to
go to a group, because we're supposed to do physical exercises, and
I'm just at the stage now that I think it would be better to go to a gym, because you start on a Monday you say, but on a Tuesday you're in a hurry you don't get it done, and I think if you've got something booked up you do go, and it's the same with this really.

It's kind of like a (. ) a part of the diary. Yeah. Ok (. ) umm (. ) obviously the diagnosis of Parkinson's is a very (. ) hard hitting, and quite upsetting. Have you felt that the group has helped with that burden?

I think so, yes. Because umm (my husband) wants me to go along to the group to meet the others, which I will do now in the next couple of weeks. Umm so I can meet them. But we went on a walk for Parkinson's last year, and umm (. ) you know we I met the other people (. ) in the group, so umm from that point of view (. ) it does help, and I think, yeah it is (. ) hard-hitting. The only thing I'll say about Parkinson's is (. ) umm (. ) by the time you're diagnosed, you've probably know you've got it. Umm a colleague of my father's had Parkinson's. And you know, once (my husband) started shaking, and I noticed he wasn't walking as well, I thought oh my gosh I think it's Parkinson's. And you're in a bit of disbelief, you think it'll go away?

For a while, but we realised after a while that it wasn't going away, and a doctor friend of ours, you know he noticed it as well, so by the time he was diagnosed umm (. ) you know we knew anyway. And umm what helped is, I looked up and it's not life-threatening, it's life-changing, but once I saw that it was not life threatening, umm (. ) that eased it a bit. Umm (. ) but (. ) the fact that this is something positive that we're doing does help. Yeah? It really does. I mean at the moment, we've talked this through, we don't want to go to too many groups, because (my husband)'s still fit and well enough (. ) to go out for the day, to go to the rugby on his own (. ) umm so you don't want like Monday: one Parkinson's group, Tuesday: another, because (. ) he's fairly well he is mobile, umm he can dress himself, he's communicating well, so at the moment, we umm, you know we both decided we don't want too many groups on the group, but I'd
say this one it's umm, it's not too heavy either the group if you
know what I mean, it's it's not a heavy group, he's obviously having
a lot of fun there (.) as well. But I know we've accepted that he's got
the Parkinson's (.) umm and you know we're making a life around it,
but to go to groups like this does help, yeah. Most definitely. Yeah.
You know, especially (.) when we went on the walk I was able to
speak to other wives as well. You know, I suppose husbands of
women with Parkinson's, it's opened I suppose a life to us umm of
people with Parkinson's, and you're able to openly share
experiences then, you know? Yeah, the groups do help for the
spouses as well, that you can you know see how other people are
dealing with it, because people are slower (.) with it, that can be
hard as well, you know. But, you know that other people are going
through the same so uh, yeah.

I:

[ ] Oh great, well that's good to, you know (.) umm [3] yeah you
mentioned other kind of activities that, so the walk, umm (.) have
you found (2) umm (2) has (your husband) made any kind of (.)
friendships as a result of joining the group?

[ ] Yes he talks about, he's not (.) meeting them outside of the
group yet, but he is making friends there, most definitely. He comes
home and talks about (group member), people within the group and
it's a mixed group isn't it as well, so you know he comes home
talking about, you know the men and the women (.) in the group,
and uh when he went for the walk, he was saying oh, I don't know if
he was called (group member), or (group member) over there, one
of them was involved (.) quite heavily with the walk, and then he
saw someone called (group member), I don't think (group
member)'s been there for a while but I met, but it was good to talk
to (group member)'s wife (.) as well, but he saw someone called
(group member), he saw a lady on the walk as well, and he saw
people from the Parkinson's group who sometimes turn up you
know? Whether it was (lead volunteer) or I don't know if it was the
lady called (group member) there. We went back to umm, whether
it was the museum. We went back to a building (.) and it was a social
event after, (my husband) was introducing me to friends he'd made.

But I would say most definitely, he is getting to know people and

umm make friends there, which uh (.) which is good. You know, and

um (. ) you know (.) hoping, obviously (my husband) will keep going,

but these other people will as well, and uh, as I said. It's not just,

they talk about Parkinson's, he comes home and talks about ( )

other things like they've talked about rugby, or holidays is a big

thing as well. He says 'oh, someone's got Parkinson's, and they've

just come back from Turkey', and then you think, yes, well having

Parkinson's shouldn't stop you from going to Turkey, so (.) you

realise that other people are doing with their lives, so as well as the,

you know, the speech, umm the fact that people are travelling, and

they're doing other things with their lives, it's not just determined

by the Parkinson's. I'm sure he said one person has been to Egypt,

someone had been to Turkey, yeah, so umm (.) it makes us realise,

you know, that you can still travel and so things, yes. So uh, yeah

he's definitely making friends there.

Yes. Would you describe the group as kind of being a ( ) a relief

maybe, or a relief ( .) kind of a ( .) break, as it were, from the disease?

Yeah. I mean, at the moment, umm you know I hope it stays

like this, (my husband) is sufficient, so today he met me in town,

he's capable of going for the train and coming into town and (.) it's

awkward if he orders a coffee, because his hand is shaking, so it has

to be brought over, but we pick sort of cafes like Coffee 1 at the

bottom of (street), when you know they'll bring ( .) you know coffee,

or whatever he's buying over. So, I suppose I'm less in need of a

break than someone who's a full-time carer, because at the

moment, I wouldn't, you know (my husband) can dress himself ( ),

shower, go to the rugby and meet his brother, so umm ( .) when I say

a break, I mean when you're both retired. I'd say we're in that

position that you need separate interests, and a break from each

other, just to have something to talk about. So from that point of

view, it would be a break like any other retired couple, but you
know (.) umm I wouldn't say (my husband) is (.) demanding of me from a care point of view (.) at the moment, you know? And you know hopefully it will stay as I said, you know generally, he can dress himself, he can go down and catch a bus or a train, he can get himself around, so (.) he is independent, and uh hopefully he will stay like that for a long long time, so you know I say it's a break, a break like for any (.) married couple (laugh) that's retired, that you know it's nice sometimes to have the house to yourself, or you know I do a bit of shopping while he's in the class, because it's his friends and his space really as well, so uh yeah. But I certainly wouldn't take it as a break from looking after (my husband), because he can look after himself. Yeah. You know, somethings I've got to put cuff links in for him and things, but (.) at the moment, he's not doing too badly.

I:

ok yeah good. That's nice. It's nice that you've kind of both got roles without your roles having to be kind of like a carer to him, and having that kind of (.) burden.

I'll tell you what it has helped as well, can I? It's that (.) he's gone into the church choir, yeah. It's only a small choir in (church), but I can hear, the other day, I can hear him. Umm, so cos he (.) sung in a choir years ago and he's also known to have a lovely singing voice, and he's said his voice has gone. Well (.) this was before we knew it was Parkinson's, and I thought: how can you voice go? But he was right, the Parkinson's was there. But now he's got the confidence, and this church choir, it's only a small one but a couple more people have joined, and they (.) you know they're trying out different hymns, you know and different (.) ways of singing and that, so I'm really pleased, and that's helped him, and with (.) he's gone to a choir and he's making friends there as well, so I've noticed a few (.) he come home with a few Christmas cards from the choir, but through keeping his voice up, it's umm (.) given him the confidence to go into (.) this choir, he is needed there as well.
I: Yeah, well that's good that he has a role there. I think, do you think the group is kind of been a, kind of led to that, that, do you think the group has allowed him to do things like that which maybe he couldn't do before?

K: I think so, yes. You know especially when they said, you know that his voice, it is improving, and of course the choir plus the class, the one is helping the other, so umm. So we're really pleased, but going to the class and you know you're working on the voice as well, umm well obviously can be a benefit to the choir, I think, as well.

I: Help each other, yeah. Really good. It seems that he's living really positively with it you know? Because I know, for some people, it really, I think they have a really difficult kind of adjustment and...

K: Yeah. (My husband) has never once moaned or complained about the Parkinson's. He was in the fire service, a really active life. But, at no stage has he ever moaned or complained about it. He's um, he's really pleasant and easy. It can sometimes be hard on the spouse because things are slower. Umm so at the hospital they've told me to allow more time. You know because the consultant said if it takes twenty minutes, allow forty. Umm and there's no other solution, really. That if you, like even with the

the more you knew before, you know, I've got to make, allow a couple of hours, because I like him to go smart, so you know a couple of hours to make sure you know he's showered, shaved, dressed. I mean we get up but, you've got to allow the time and time to get there as well so he's not rushing. Because the balance is a worry with Parkinson's, and once you start rushing, it does make the balance sometimes a bit worse. Well if it gets stressed. So uh, as I said. But no he's never once moaned or complained. He's amazing, he really is. He's just, well he's just great. As I said he's probably more laid back than I am, so umm, you know if I see we've got to be at the For 1.30 isn't it, and I just say to him allow time and whatever. But you know on a Thursday that would be the
focus for the latter part of the morning for getting there. No, he's.
he's fine.

▌: Yeah, that's great. Umm (2) I know that you mentioned you
don't attend the group with your husband, and you've said that
you're thinking maybe of doing that in the next few weeks. Would
you say that's something you'd like to do or would you see it as
quite separate?

▌: Umm, well (my husband) has asked me to come along. I think
he wants me to (. I meet umm the people who run the group, the
students who come along, and to meet his friends. So umm () I
don't, there's a reason why I couldn't go () this week after
Christmas, I think I was just busy after Christmas and everything.
and I'm () quite busy on the governors of a school and I had a
meeting there, but there's () we're going to miss next week because
we're away, but I said then () after that I will come along, and umm
and meet the group. I'm not saying I'll come every week, because I
feel it's his space, it's his identity, it's his group. You know if he
wanted me there for support, I would go, but if he can deal with the
group on his own, then I think that it's better that I step back and
you know, let him go along and enjoy it and mix with the others, and
uh. But, he he wants me to go along, there's no problem with that.
I'll uh, I will. We have got busy lives, so I suppose the Thursday
afternoon just frees me up to catch up on shopping or you know
other things really. But umm, as I said, I will go along for him in the
next few weeks to meet his friends and the leaders of the group,
and umm, if they want to ask a couple of questions than that's fine,
yes.

▌: It's really nice. Umm (2), let me look at the time. Ok, umm (2) I
think we've covered everything.

▌: The only thing he did ask me before coming was for me to find
the best exercises he'd done in the group. Sorry, I've got stuff here.
Umm () he said there was an exercise they do back to back, and
they have to shout to one another, and he's asked whether I would
Try this with him at home as well. Because he found it really good.

As I've said, you sit here, you've got someone sitting behind you, and you call to one another? And

Yeah, I think it encourages to like, because obviously if you're face to face, you pick up on things. If you're back to back, you can't see

That's it! He said of all the things he's done, that is the best. And it's something you know we can quite easily do at home, and then he said there's an exercise with a ball, and you count at the same time as catching?

Yeah, oh. I know we did an exercise where you roll the ball and you have to think of things, like you count up to hundred and then back again. I don't know whether that might have been it or something similar.

It says you count out as you catch the ball. Anyway, he said they were the two best, but he's really enjoying. So it's giving us ideas as well, you know, and he's so keen (.) that he stays engaged (.). When we're out with people. Because umm, one lady we've got in our church, she's got Parkinson's, she was a friend, she's a teacher, and her mind is still fine, but her voice is so quiet that you've got to go really to listen to her. Umm but I mean she's a lot older than [my husband], so it could be old age as well, and not having the same energy as a younger person. But umm I go to a club in [area], a Welsh club, and I've noticed that a couple of people have got husbands there, and they're not really joining in? And I wouldn't want that to be (.) (my husband), you know to keep his volume of his voice up and, to keep him chatting with people, because I know he likes company and that. Also, he goes out now on a Friday night with the neighbours, and again you're in a noisy pub environment, and he's dealing with that better as well now. You know? They go out from 5 until about 7 o'clock on a Friday, and umm he is, yeah.

Because I said can they hear you, and he says yes and I'm engaging...
in conversation with them, so umm, so that's good you know? You know, I don't think he'd want to just go out and just be sat there.

E: No, I think he wants to keep engaged.

L: That's it, and uh, as I said. He's doing a lot with his voice, he's singing in a choir, he goes out with the neighbours, quite sociable as a couple, umm I feel that, when he's tired, the volume of his voice goes, but if we're in company, I give him a sort of (gesture), you know alright sometimes I say to him, (name) make sure you know people can hear you, so umm. Because I think that's the hardest part, I think I'm talking loudly. But umm, yeah I'd forgotten about that, he goes out with the, with the neighbours as well. But he said of all the exercises that back to back is brilliant. Now the last thing, I do at home is umm (.) when the radio's on (.) umm I tell him to talk over the radio, because I was a teacher and I suppose, I have quite a loud voice (laugh), you know? Umm I've said to him to talk over the radio to me, you know? And to do that, umm because they've checked his vocal cords and they're in good condition, there's not any bother with his throat or anything, umm you know I'm probably more hoarse than him from years of teaching, but uh (.) you know to. I said if, another thing I've said to him as well, 'if you start shouting, I can always tell you to perhaps, shout at (my husband) and bring the volume down. But if you're quietly spoken, it's more frustrating isn't it.

E: Yeah, and that's sometimes your personality your voice.

L: Yeah. What made me think was we got a friend of ours, I think he really should have gone for some sort of treatment because you can hardly here what he's saying? And it has affected him socially, most definitely. You know, out with a group of friends, and whether it's a confidence issue or what, but you just can't hear him anymore, you're straining to hear, and it can be quite exhausting for people, but umm. But no, we've only got positive things to say. So in summary, say 1) it's helping his voice (.) umm the companionship (.) he's loving, umm the sort of mental side to it, you know you've got
to relate stories (. ) umm read poems and look for poems, that's good. You're with fellow Parkinson's patients, you know people, so you can share experiences of the ( ) Parkinson's, you know like mobility, balance ( ) sleep patterns, because it can affect your sleep.

So, you're sharing experiences as well. Umm so all in all, it's umm really positive, and as I've said, he's definitely making friends, he comes out from there beaming, so we do make that Thursday group a focus for us, yes? So umm, I definitely, I hope, you know, what we would do if they stopped it really?

I:

Oh no, hopefully it's indefinite for now.

Yeah, and the other thing is umm, they say to do these exercises at the hospital, but it's a bit like I'll go to Welsh classes, they say practice in the week.

Yeah, sometimes it goes like that, gone.

It's things, other things get in the way, but when you've got a class, you've got to go, and umm yeah. So thinking you know, from that, he's joined a choir, he's engaging better with the neighbours as well, you know, and he goes out to the pub, so umm, and I'm finding that less and less, people are asking 'can you speak up a bit (name of husband)' or 'I can't hear you'. So umm, we're really grateful for people running the group, very very grateful. It's a lovely thing, I don't know whose idea it was, the group.

I'm not sure, I think it

Was it (the lead volunteers)?

Yeah they kind of run it, then but I think they have a kind of oversee it? Then the SLTs like the therapists (name), I think they kind of help with it as well, like make sure it's running right so yeah, thank you for participating.

Well it is important you know when you're ( . ) you know it might be with the husbands have got dementia or something, they're a lot older than this (club), they're just sort of sat there?
462 Umm the other thing I do mind to help (my husband's) speech (.) is
463 he used to be an avid reader, ad things is something for the speech.
464 And he's not reading a book as much, but I say read the papers,
465 because my mum is 87, she reads the paper, she's got so much stuff
466 running through her head, and that will help you with your speech
467 as well won't it? And they also say, you know when I was teaching, if
468 the children have a lot of experiences, that makes you talk as well,
469 and it also. So um, I'm trying to, like I said, he's also into rugby and
470 football as well, because when you're out with people, everyone
471 talks about football, especially (name), but I tried to say keep
472 yourself like (.) reading up on stuff (.) like that, and football's easy to
473 talk about isn't it? And obviously rugby, he'll talk all day, but to keep
474 yourself (.) informed and up-to-date, and that can help speech can't
475 it? You know, we do try, we go away, we're off to (place) next week
476 so.
477 : That's really good. Thank you.
7.10 Joanne – Analysed Interview Transcript

3

Interview (I): Ok this is an interview umm an interview about the
spouses’ experience of attending a Parkinson’s support group umm
so this is a general chat about Your experience of your husband
attending Parkinson’s support group umm (.) yep ok. So just to start
umm how long is your husband been attending the Parkinson’s
group?

Joanne (J): Any Parkinson’s group or particularly this?

I: This particular group.

J: Umm (.) What would I say, might be a year? Yeah?

I: Ok. That’s fine. Is it often? How often is that?

J: Every two weeks yeah. He very religiously attends every two
weeks.

I: Ok. Can you give me a brief overview of what the group does?

J: And they seem to have a mixture of, they have seem to have some
physical exercises To warm them up I think umm And then they just,
they do lots of different exercises (.) like funny games funny rhymes,
amm stories, I think they get into small groups. I’ve never ever
actually been in myself. They get into small groups, small smaller
groups, umm they you know discuss things in small groups. Umm
but they seem to have basically fun (laughs).

I: Yeah. Umm (.) what’s your experience of umm the aim of the
group? What would you say the aim of the group is?

J: I think it’s just to (2) certainly maintain (.) the sort of the speaking
ability and the volume of speech and everything, I don’t, I don’t
know whether it would actually improve what they’ve got, but I
think it’s to maintain what they’ve got.

I: Ok.

J: And I think it’s to making them more (.) prepared to talk.

I: So not just the (.) loudness also how or what they talk about?
J: Yeah I think probably.

I: Ok. Umm (2) so (.) what do you think are the key things that motivate (your husband) to attend the group?

J: Umm. I think it's just to keep, keep his voice. I think he gets quite a lot out of it socially, and he's joined quite a lot of Parkinson things, which have (.) have got him out the house. I go with him to most of them, but it does get him out of the house, and meeting other people, and not sitting at home being miserable.

I: Have you found that's made a difference, him actually going out and things?

J: Oh yeah. Yeah, the whole lot of umm. So we started going to Parkinson's café? And then really, it was only through that that we found out about (.) [redacted] you know as soon as you start going to anything, you hear about other things that are available.

I: Yeah, ok. Umm (2) so have you noticed umm a difference between (your husband) from attending the group, so before and now?

J: Umm (3) at times. I think it's one of those things, you know, it depends what his mood's like. Sometimes he can be just so quiet, and you're constantly saying you know like 'pardon? Can you repeat that?' Uh I've got three grown up daughters, and they saying like you know, but it comes and goes. You know sometimes it's absolutely fine (.) umm but he doesn't seem to remember, you know, you've actually got to turn and face someone when you're talking, and lift your head? Because he seems to turn away, and he's talking sort of (.) you know at the desk and expects people to hear him. He seems to have forgotten that, and a lot of it is face to face contact.

I: Hmm yeah.

J: But I'm just assuming that it's making the, it is maintaining what he's got, not just sort of (.) losing it.
I: You say that it's maintaining it? So it's almost like at one level, do you think there's a chance that he could, not just with his voice, but any changes in his mood, like wellbeing?

J: Oh, I think yeah. Oh I think yeah that's improved a lot. Yes, compared with, because we only really started going to these, any of these things two years ago, and compared with that, I mean he is much better you know? I think it's just a mentality you know? You sit at home and sort of [.] slump, and you, sort of having to go out to all these things, it makes a huge difference.

I: Yeah. So from your perspective, umm as his wife, umm have you kind of gained anything from (your husband) attending the group?

J: Oh yeah. Yeah.

I: Can you tell me a bit more about that?

J: Umm (2). Well I've found it good that it's one thing I don't go to, because that's quite nice that he can come home and tell me about it, which probably helps. Umm and I think he, compared with a lot of the group, he's probably a lot more outgoing, so that's, I think he's thinking, you know he's [.] doing quite well, that he is [.] still you know making his voice heard, above other people, you know? I think he's thinking 'ah I'm not as bad as I thought I was'. Which sounds a bit [.] selfish but you know...

I: No I get that. I think, yeah, makes sense.

J: I know that when I started going to Parkinson's groups, I was afraid that you see people really bad, and then you'd get depressed. But it's a mixture of, you know you do wonder whether it goes down that route it's not good, but [.] you also feel that even if people are bad, they can still keep doing a lot of stuff?

I: Yeah, I get you. Yeah it makes sense. Yeah [.] With umm (2) so more from your kind of perspective as (X)'s wife, umm (2) do you feel that the umm (2) the group is a kind of uh break in a way, maybe from the Parkinson's burden?
J: Umm. Oh for me.

I: Yeah, how would you describe it from your...

J: Yes. I think the fact that I just drop him off, and yeah. Because, like
yeah. Most of the other things we do go to as a couple, so uh, yeah
24 hours a day.

I: Yeah.

J: And I think the, you know, the same people seem to go, it’s quite a
(.) you know the continuity is there, you see the same people (.) and
you know, they all get on very well, and yeah.

I: Yeah, ok. Um (2) has the group allowed you to do anything that
you previously weren’t able to do?

J: Umm so me or (my husband)?

I: Umm well, both of you. So (your husband) and maybe you.

J: I don’t think so. Because he was always prepared to you know
stand up and speak in front of people, he was always prepared to do
that but I think (2) maybe he’s, it’s made him realise that he can still
do it. So yes, he still will, so you know, stand up and speak.

I: Yeah, yeah.

J: I find that he’s a lot quieter in (.) like social groups. Because I was
really quiet, but I could always leave him to do all the talking if
necessary. Umm so I find it’s sort of like, you know in a family group,
he’s quiet now compared to how he used to be.

I: Would you say quiet as in, his volume’s quieter.

J: No, more like less to say.

I: Yeah, like more withdrawn. Ok, do you feel that the (2), because
he’s with the, do you feel that the volume has an effect on the fact
that he’s withdrawn? Like a link.
J: Yeah I think it’s partly that, but it’s partly, you know it’s not wholly

(.) wholly the volume. I think you just get a bit more, you know,

introspective, and think rather than speak.

I: Yeah? And how does that affect you?

J: Oh it makes things harder work, you know. But you get used to it,

like you get used to it.

I: Yeah. I just wanted to talk about umm (.) (your husband’s)
diagnosis. Obviously it’s quite a subject to you know, it’s quite
emotional and I don’t want to pry too much, but umm (.) so when ()
(your husband) was diagnosed, did you (.) how did that feel?

J: Well I, I guessed what it was before he was diagnosed. Umm (.) so
when he had quite a few symptoms (2) there were various
alternatives that I was thinking it could be. So Parkinson’s was
probably the least bad. There were sort of worse alternatives, you
know I was thinking (.) brain tumours and I don’t know. motor
neurone and all of these. So it seems that in some ways, Parkinson’s
was, you know (.) the best. Umm, but I think it came as quite a shock
to (my husband), he hadn’t even considered it.

I: Yeah (2) yeah ok. Umm since the diagnosis, have you umm (.) have
you found LiveLoud! Has changed your view on the diagnosis and
the future? Has it helped in anyway?

J: (2) Well it’s helped, but umm. I saw something, if professional
people are doing it, then they must, they must think (2) it will help,
you know? Yeah, you know, if it’s just other Parkinson’s people that
have sort of thought, we’ll get together and do it. But when you
think professionals are sort of leading it, then you think it’s (.) it’s
obviously something that is worth doing.

I: Yeah, so you know, kind of any little helps in a way. Yeah, so
professionals are running it, yeah ok.

J: Yeah, I suppose it gives you confidence (.) you know that they’re
know what they’re doing.
I: Yeah, yeah. Ok. Umm would you say the group has umm changed or (.) influenced your daily life (2) in anyway?

J: Umm (2) no I don’t think so.

I: Ok. (7). What has the group allowed you to do that wasn’t (.) there before? Has it allowed you to change, to umm (.) do something that you weren’t able to do before?

J: Me personally?

I: Yeah.

J: Umm (3) no I just get two more hours out of (.) I go to the gym usually (laugh), yeah I go to the gym.

I: Yeah, a bit of time, kind of, something that’s not related to the (.) yeah, something different. Ok. Umm (4) could you tell me a bit more about some of the benefits that you see as (.) for you, even though you don’t attend, is there anything indirect benefits that you get from the group?

J: (2) Well he does talk about other members of the group (2). And some of them ares people I’ve met through other, so umm (.) And some of them do, not physically get together, but they sort of email each other, so they (.) plan, if they’re going to do something, sort of jointly (.) next week they do get together like that.

I: Hmm, yeah (3) so a friendship in a way?

J: Yeah, yeah.

I: Have you been umm (.) you said you’ve been and you’d met up with some of them via...

J: Yeah yeah, so previously, some of us were on a self-management course that (my husband)’s on, and I was on with him. So we yeah, one of them was on (.) on the same course so. And I give a lift home to one of them occasionally, so yeah. She’s been active.

I: Ok (4). Umm (6) you mentioned you don’t actually attend the group, is there a particular reason for that?
J: No, I thought, I think it was when was, it was when (my husband) first heard about it. I think I assumed it was only for Parkinson patients, umm, so I think it’s, it’s probably better off (2) going by himself, and not having me as a sort of audience. And I don’t like joining in with that sort of thing.

I: No that’s fair enough. Yeah.

J: I don’t know whether, do the partners actually ( ) do the same exercise, do they as the...

I: Not really, no. I don’t think many partners go to be honest. Umm I think it’s just sort of, the individual tends to go. Do you see the group as a way of (your husband) being independent, and kind of doing his own thing?

J: Yes, I think yeah.

I: Do you think that’s important?

J: Oh yes, yeah.

I: Yeah, can you tell me a bit more about that?

J: Umm ( . ) well I think it’s most groups we go to, we typically go to as a couple, so it’s ( ) nice to think, you know I can just drop him off and forget about him (laughs) for a couple of hours.

I: Yeah, definitely.

J: And I think he’s always got on well with ( . ) (lead volunteer)? Yeah, (lead volunteers). We know (lead volunteer) through management as well, so umm yeah, so he knows her well, from that. And I think it all seems quite inventive, and the different things that they’re doing.

I: (3) Yeah, ok. Umm yeah you said that (your husband) is quite, he’s quite, in this group, he’s been able to do a lot with and have a bit more of a role.

J: Yeah, I think he’s always, I mean he always was ( ) happy to, sort, talking and giving presentations and stuff, but I think ( . ) he probably thought those days were gone, you know, that he would, would
want to do it. But he’s, you know, more than happy to stand up in
front of people. Although he does stutter a little.

I: Is that from the Parkinson’s?

J: Yeah.

I: OK, that’s interesting. (3) Has uh (. ) did you have any concerns of

umm, when (your husband) was diagnosed, that there would be

changes to him, like how he is and his personality?

J: Not really, I really thought what it was, just a physical thing? You

know, a shaking? I think that’s what I assumed would get worse, but

it’s uh (. ) I didn’t really think it was the sort of, the whole package

with, you know, voice and swallowing, and uh everything. It’s

anything, it’s like, you know it’s bowels and all of it, it’s sleeping and

you know turning over in bed, and all of these things that you forget

about.

I: Yeah, yeah.

J: And I think getting a bit withdrawn (. ) you know, it’s probably the

same as any diagnosis that’s uh. And I think when it’s (. ) it’s termed

as umm it’s getting worse, what is the word?

I: Degenerative.

J: Degenerative. Yeah, I think when you hear the word degenerative,

you think oh you know.

I: Yeah. But through the group, do you think that (. ) umm the
degenerative label (. ) obviously it’s still degenerative, but there’s

some kind of improvement?

J: Yes. I think so, yes. When we when (my husband) was diagnosed,

it was a case of the chap said something like ‘you’ll have 5 good

years’ or something, and you think ‘oh god’, you know? At sixty

something, and you’re told you’ve only, well, it seems like 5 years is

long, but it goes quite quickly, and you think, 5 good years and then

what you know? The medication will work for 5 years, and then it

will sort of not work so well, and then, so I think it’s at the
beginning, you can sort of sit at home and think, oh you know what’s going to happen? But umm, yeah I think, when you go out and meet people who've had it for (...) you know 10 years and 15 years and (...) umm you realise it doesn’t suddenly stop, you know?

I: No (2) Umm yeah, I know it’s a (...) it says 5 years, people live longer and are able to live ok with it longer and things.

J: And I think, since (my husband’s) been diagnosed, they seem to (...) well to us, they seem to have suddenly said how important things like exercises are? And presumably it’s like vocal exercises as well as (...) physical exercise you know.

I: Yeah, I think it’s like a use it or lose it type of thing, you know keep going and you’ll see that it doesn’t go down as much as, good. Yeah, yeah ok. Umm (?) has the group kind of given you any umm (.) reassurance about the future? (.) With the Parkinson’s.

J: Umm (4) I suppose that yeah, I think so. I think that when you hear of people having it (.) for so long, and they’re still going out to these groups, and umm. You know, having a social life and stuff, but yeah.

I: And what do you think that (your husband) values most about the group?

J: (3) I think it’s just the hope maybe? The hope that it will sort of stop things getting worse or slow down things, just to you know, sort of maintain what he’s got now.

I: Ok. Ok (2) no that’s fine (10). Is there anything that (your husband) has kind of talked to you quite a lot about from the group that he really enjoys or he sees as useful for him?

J: Umm (2) he said that about the things where he has to say something, assume a different voice umm (...) some sort of speech but pretending you’re a judge or something or something funny like that. Yeah (,) I think he was saying that when they get into groups, some of them really, some of the people don’t say anything? So he
finds, because he doesn't like, well in those kinds of groups he
doesn't like gaps, so he just sort of talks (?) so maybe he's thinking
other people (?) aren't getting as much out of it as they could.

I: Yeah (3) yeah. Do you think (your husband) makes the most of the
group from how he compares to others?

J: Yeah I think so.

I: Yeah, ok. (5).

J: Yeah, I suppose it all depends on the individual, because (my
husband) (?) he I think he's part of Parkinson's as well, you get:
fixated on things? You know (?) I mean he wouldn't miss a (_____)
Session, and he goes, he does his (_____). And you know, it has
to be something vital for him to have missed, for him to miss a
session of that. Umm (.) but I suppose it's quite a good discipline,
you go there (.) you get exercise done or (?) and you know, you don't
have to sit at home thinking 'I should be exercising', you know?
Somebody is there, telling you what to do and you know it's done for
the day then.

I: Yeah (2) Yeah, ok (6). Has (your husband) spoke about any
friendships he's made from the group?

J: (6) Nobody new that I, because I tend to, he tends to mention
people I said I've met (2). Because otherwise it's a bit difficult to
explain to you, to explain to someone who they are, so people tend
to talk about people that I've met elsewhere.

I: Yeah, ok (.). So (your husband) talks about quite often about what
the, chair is very squeaky, about, not just the umm the people that
he works with, but also how he kind of, what he gets out of the
group? Umm (2) let me rephrase that (5). Can you tell me a bit more
about what (3) (your husband's) attitude to the group and how his
(2) umm disease (2) his umm (.) trying to rephrase this, it's quite
difficult. Umm (.) how he views his disease now as maybe (.) the
result of attending this group and also other Parkinson's, how would
he, how would you think he now sees it?
J: Uhm [5] well I think he sees it now as something that you can live with it for a long time. Umm as I said, not just sitting at home waiting for uh, for it to get worse and (2) you know, things that we, that we do or he does (2) umm (.) are to sort of slow everything down, or to you know make it not progress to the same extent. So he thinks, I think he thinks, you know he can make a positive difference to uh, to the disease I think.

I: Yeah, and he can kind of (.)

J: You've got to be able to control you know? He's making the decisions to go to these things, and go to exercise classes and things, so you know, it's good that he, he can make a decision and you can hope that it will improve things for you. So that gives you some power doesn't it?

I: Yeah, it's that kind of (.) that power over, that thing that you can't control, it's quite important. Yeah.

J: Yeah, I suppose if it was, for the first few years, it was a case of you know, you've got it, that virtually you can't do anything about it, you know, take the tablets which will help a bit, but there's nothing you can do to umm (.) improve anything yourself? You know like, you know (.) positive attitude, nothing will help. But umm, I think you know the last few years is when, you know, he learnt that there are sort of these therapies that sort of, which will (.) improve things or (.) or let it, you know, plateau.

I: It's sort of amazing how powerful a (.) a specific attitude to something is you know? If you're positive towards something, you're more likely to, indirectly you're more likely to put that in place, which is obviously going to help, or least maintain something. Yeah.

J: The thing is now is that he's got to a stage of (.) you know you accept everything, everything coming in your direction, you say I'll do that, I'll do that. So it gets quite like a full-time job? Yeah (.) so (my husband) has to say (.) I can't fit it in anymore, you know? I've
got to stop now, but I think, he’s got so much more energy now then he had when he was doing nothing.

I: Like a new lease of life in a way. Yeah that’s interesting. (5) I thought of something, I can’t think what I’m thinking of. Umm [3] is uh (.) do you feel that there’s obviously a lot with Parkinson’s, and it takes up a lot of his (. ) spare time (2) do you think that (2) it’s good to have his mind occupied, or do you think he needs a distraction from the Parkinson’s? Because obviously he (. ) if he’s involved in a lot with Parkinson’s UK, he won’t have any kind of escape from it?

J: Yeah. Umm I think it’s actually, it’s helped now that he seems to be doing, he did, he’s doing stuff outside Parkinson’s, which he wouldn’t have been doing a couple of years ago? You know like going out with people he used to work with more regularly and umm (2) trying to think what else. Umm but yeah, I said in the first few years of umm diagnosis, there were a lot of things that we did that he sort of said ‘I won’t be doing this again’, you know like making him go to the theatre or something, or, because he gets a bad back from Parkinson’s, and he would be like crippled with a bad back, and he would say ‘I won’t be able to come back and do this again’, and then eating out. Umm(.) oh yeah, I won’t want to be eating out, because cutting up food is quite awkward? Umm but I think the more he’s done, he’s stopped feeling like that? You know he’s stopped feeling like these other things will be stopping very soon. So that’s a, that’s made a big difference because it’s quite depressing when you think ‘oh well’, when you say ‘I’ll never be able to do these things’ again, it’s quite uhm, it makes everything worse you know?

I: Yeah, because you might as well try, because then you know at least you’ve... because you can’t do these things, but then, if you don’t do them, you won’t do them anyway.

J: And I think it’s because you’re mixing with people with Parkinson’s. I think before, probably (2) never really seen anyone, or spoken to anyone with Parkinson’s so it’s by going to things with
other people, and hearing that, you know, they're still doing things, you know? They're still going on holiday, they're still going out regularly, and so I think that's all helped that you can (.) you know you're not like embarrassed (.) by it, you know, like if I say, you know, 'can I cut that up for you?' in a restaurant (.) I mean I don't care, you know, having to do it, but I think he would have been a bit, you know upset, if I'd sort of suggested it. But now I say, don't worry, just you know, if you need a hand then un, just accept it and at least it means you can (.) do things that you otherwise might have said, oh I'll stay at home and eat.

I: Ok (2). I think (.) I think that's everything. Thank you.
### Amelia – Clustering of themes

Amelia: Table of Chronological Emergent Themes and Clustered Emergent Themes

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<td>Education of functional impact</td>
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### 7.12  Amelia – Master Table of Themes with Verbatim Quotations

Amelia: Table of Themes from Interview Analysis with Verbatim Quote Examples

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<tr>
<td>Reduced emotional dependence</td>
<td>269-271</td>
<td>’one of the things like I said is his slightly more independence (.) for him, and I’m not afraid to do that now? ’</td>
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<td></td>
<td>155-157</td>
<td>’I think that this (.) has helped me to realise that I’ve got to let him do or try and do (.) everything that he wants to do’</td>
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<td>Reduced self-monitoring role</td>
<td>147-149</td>
<td>’I think it’s made me (.) umm (2) more aware of, I think I did too much for [my husband] (.) when we first (.) before we attended these thing’s</td>
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<td>’I can see how they deal with and you know individuals themselves with Parkinson’s deal with it’</td>
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<td>’it can be a bit scary because you can see people who have had Parkinson’s for a lot longer and how it affects them’</td>
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<td>154</td>
<td>’just seeing what the other men for example (.) do and they manage to do things’</td>
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<td>Comfort from comparison</td>
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<td>’(the friend)…he’s obviously physically quite (.) bad as well (.) umm and (2) it’s made me realise how lucky we are’</td>
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<td>Comparison in participation</td>
<td>289-291</td>
<td>’[another group member] who’s not here today, you know the fact that he comes here on his own’</td>
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<td>Applying techniques in daily life</td>
<td>242-243</td>
<td>’as (.) [the lead volunteer] has said to do, that if you go out in the social, he’s been proactive (.) in sitting between two friends’</td>
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<td>Catalyst for changes in social participation</td>
<td>373-375</td>
<td>’it’s not just the progression in (.) umm his speech and (.) communication, but also physically and his general well-being’</td>
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<td>174-176</td>
<td>’it just (.) makes it (.) easier to make (.) to change to make the changes in your own lives, that you have to make’</td>
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<td><strong>Facing inevitability positively</strong></td>
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<td>Catalyst for progress</td>
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<td>’you tend to think that when the diagnosis is given it’s all going to be’</td>
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<td>109-110</td>
<td>downhill (...) but we know from coming here that it’s not’</td>
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<td>‘[my husband] relaxes when he’s here (...) because he’s with people who are (...) in the same position as he is’</td>
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<td>Group support</td>
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<td>‘he feels safe when he’s here (...) when he’s amongst people who understand what Parkinson’s is all about’</td>
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<td>59-60</td>
<td>‘it’s not just a social, they’re not just a social function, they’re friends (...) you know?’</td>
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<td>‘it’s just like as if you’ve been on the tour club, you know?’</td>
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<td>Social participation</td>
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<td>‘it’s like a camaraderie really’</td>
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<td>Dependence</td>
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<td>Dependence on group’s longevity</td>
<td>187-188</td>
<td>‘I’m hoping that they’re going to run forever’</td>
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7.13    Karen – Clustering of themes

Karen: Table of Chronological Emergent Themes and Clustered Emergent Themes

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## 7.14 Karen – Master Table of Themes with Verbatim Quotations

Karen: Table of Themes from Interview Analysis with Verbatim Quote Examples

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<th>Examples</th>
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</thead>
<tbody>
<tr>
<td>Burden</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced self-monitoring role</td>
<td>100-103</td>
<td>‘because I’m more relaxed out, because if you’re out with someone, and you feel they’re being left out of the conversation, you’re not as relaxed, because you’re worried about them.’</td>
</tr>
<tr>
<td></td>
<td>109-111</td>
<td>‘I’ve noticed recently. We were out on the weekend, that I’m not asking him to speak up as often.’</td>
</tr>
<tr>
<td>Types of comparison</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comparison in ability</td>
<td>424-426</td>
<td>‘a friend of ours...and it has affected him socially, most definitely. You know, out with a group of friends, and whether it’s a confidence issue or what, but you just can’t hear him anymore’</td>
</tr>
<tr>
<td></td>
<td>38-39</td>
<td>‘but being in a group, most definitely he’s sharing experiences with other people with Parkinson’s, you can compare with yourself’</td>
</tr>
<tr>
<td>Comfort from comparison</td>
<td>81-82</td>
<td>‘it’s the camaraderie, umm the meeting of people, you can compare yourself with other people’</td>
</tr>
<tr>
<td>Comparison in participation</td>
<td>242-244</td>
<td>‘he says “oh, someone’s got Parkinson’s, and they’ve just come back from Turkey”, and then you think yes, well having Parkinson’s shouldn’t stop you from going to Turkey’</td>
</tr>
<tr>
<td>Catalyst for change</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Applying techniques in daily life</td>
<td>409-411</td>
<td>‘now the last thing, I do at home is umm, when the radio’s on, umm tell him to talk over the radio’</td>
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<tr>
<td>Catalyst for changes in social participation</td>
<td>285-286</td>
<td>‘I’ll tell you what it helped as well, can I? It’s that he’s gone into the church choir’</td>
</tr>
<tr>
<td></td>
<td>390-392</td>
<td>‘and I wouldn’t want that to be [my husband], you know to keep his volume of his voice up, and to keep him chatting with people’</td>
</tr>
<tr>
<td>Adjusted role of spouse</td>
<td>316-317</td>
<td>‘it can sometimes be hard on the spouse because things are slower’</td>
</tr>
<tr>
<td>Facing inevitability positively</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catalyst for progress</td>
<td>128-129</td>
<td>‘but somebody said to him, that he’s definitely improved’</td>
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<tr>
<td>Page</td>
<td>Text</td>
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<tr>
<td>------</td>
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<tr>
<td>21-22</td>
<td>‘we do the exercises at home but you’ve got to be very disciplined’</td>
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<tr>
<td>159-162</td>
<td>‘it is progressive, we’re both realistic about that, but I am still convinced, if you keep exercising and keep working (.) at things like you know the level of your voice that you can help (.) help things along.’</td>
<td></td>
</tr>
<tr>
<td><strong>Active role in progress</strong></td>
<td>158-159</td>
<td>‘we’re actually doing something to (.) you know, not give in to the Parkinson’s’</td>
</tr>
<tr>
<td></td>
<td>162-164</td>
<td>‘and the fact that, we’re actually doing something about it, and that he’s seen progress now, umm has impacted on both of us, as a couple’</td>
</tr>
<tr>
<td></td>
<td>189-190</td>
<td>‘it’s not life-threatening, it’s life changing’</td>
</tr>
<tr>
<td><strong>Mutual trust and friendship</strong></td>
<td>91-92</td>
<td>‘it gives them a chance to (.) speak to people who have lived in that experience’</td>
</tr>
<tr>
<td><strong>Sharing lived experiences</strong></td>
<td>84-85</td>
<td>‘at this stage, [my husband’s] balance wasn’t very good, and he was able to (.) talk to the others about balance’</td>
</tr>
<tr>
<td><strong>Group support</strong></td>
<td>80-81</td>
<td>‘he definitely loves going to class, so the benefit isn’t just the speech, it’s (.) well it’s the camaraderie’</td>
</tr>
<tr>
<td></td>
<td>67-68</td>
<td>‘he comes out from the class beaming, saying how much he’s enjoyed it, how lovely the people are’</td>
</tr>
<tr>
<td><strong>Camaraderie</strong></td>
<td>65-66</td>
<td>‘to be honest it is, and whether we’re going on now, you know we’d both make sure that he can go the class’</td>
</tr>
<tr>
<td><strong>Dependence</strong></td>
<td>445-446</td>
<td>‘it’s things, other things get in the way, but when you’ve got a class, you’ve got to go’</td>
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</table>
## 7.15 Joanne – Clustering of Themes

Joanne: Table of Chronological Emergent Themes and Clustered Emergent Themes

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<thead>
<tr>
<th>Emergent Themes</th>
<th>Clustering of Emergent Themes</th>
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<tr>
<td>Exercises as ‘cure’</td>
<td>Group as ‘cure’</td>
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<td>Maintenance not progress</td>
<td>Social participation</td>
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<tr>
<td>Application to daily life</td>
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<tr>
<td>Social participation</td>
<td></td>
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<tr>
<td>Catalyst for social participation</td>
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<tr>
<td>Catalyst for applied social participation</td>
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<td>Role as self-monitor</td>
<td>Reduced self-monitoring role</td>
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<td>Maintenance not progress</td>
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<td>Catalyst for improved wellbeing</td>
<td>Catalyst for social participation</td>
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<td>Break from PD</td>
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<td>Time for myself</td>
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<tr>
<td>Comparison to others</td>
<td>Comparison</td>
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<td>Participation and activity</td>
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<td>Forced to acknowledge future</td>
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<td>Comparison of participation</td>
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<td>Break from PD burden</td>
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<tr>
<td>Reduced emotional dependence</td>
<td>Burden</td>
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<td>Mutual friendship</td>
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<tr>
<td>Camaraderie</td>
<td>Mutual trust and friendship</td>
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<tr>
<td>Sharing experiences</td>
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<td>Regained self-identity</td>
<td>Self-identity</td>
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<tr>
<td>Changes in social participation</td>
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<tr>
<td>Adjusted spouse role</td>
<td></td>
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<tr>
<td>Exercises as ‘cure’</td>
<td>Cure</td>
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<tr>
<td>Dependence on professional involvement</td>
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<tr>
<td>Time for myself</td>
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<tr>
<td>Reduced physical burden</td>
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<tr>
<td>Mutual friendship</td>
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<tr>
<td>Sharing of experiences</td>
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<td>Social participation</td>
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<td>Reduced physical burden</td>
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<td>Reduced physical burden</td>
<td>Burden</td>
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<tr>
<td>Mutual friendship</td>
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<td>Regained lost identity</td>
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<td>Education of functional impact</td>
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<td>Education of PD related information</td>
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<td>Facing the inevitable</td>
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<td>Comparison in participation</td>
<td>Comparison</td>
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<td>Exercises as ‘cure’</td>
<td>Cure</td>
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<td>Catalyst for change</td>
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<td>Comparison to participation</td>
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<td>Need for active change</td>
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<td>‘Hope’ for progress</td>
<td>Progress in inevitable</td>
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<td>Delaying the inevitable</td>
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<tr>
<td>‘Exercise’ – seen as a cure</td>
<td>Cure</td>
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<td>Practice makes perfect</td>
<td>Catalyst for change</td>
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<td>Topic of conversation</td>
<td>Catalyst for change</td>
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<td>Adjustment to inevitability</td>
<td>Progress in inevitable</td>
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<td>Maintenance not progress</td>
<td>Catalyst for change</td>
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<tr>
<td>Active change</td>
<td>Mutual trust and friendship</td>
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<tr>
<td>Active change</td>
<td>Mutual trust and friendship</td>
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<td>Hope for progression</td>
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<td>‘Power’ to overcome</td>
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<td>Active change</td>
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<td>Positive attitude</td>
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<td>Maintenance or progress</td>
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<td>Change of attitude</td>
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<td>Change in social participation</td>
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<td>Catalyst for change</td>
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<td>Positive attitude</td>
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<tr>
<td>Positive attitude</td>
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<td>Mutual trust and friendship</td>
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<tr>
<td>Common and shared experiences</td>
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<td>Comparison of participation</td>
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<td>Happiness in supportive role</td>
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### Superordinate Themes for Amelia

<table>
<thead>
<tr>
<th>Burden</th>
<th>Line number</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced surface burden</td>
<td>74-76</td>
<td>‘well I’ve found it good that it’s one thing I don’t go to because that’s quite nice that he can come and tell me about it, which probably helps’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>158-159</td>
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<tr>
<td></td>
<td></td>
<td>‘I just get two more hours out of (.) I go the gym usually’</td>
</tr>
<tr>
<td>Reduced emotional dependence</td>
<td>182-183</td>
<td>‘it’s probably better off (2) going by himself, and not having me as a sort of audience’</td>
</tr>
<tr>
<td>Break from PD</td>
<td>74-76</td>
<td>‘well I’ve found it good that it’s one thing I don’t go to, because that’s quite nice that he can come home and tell me about it’</td>
</tr>
<tr>
<td></td>
<td>94</td>
<td>‘I think the fact that I just drop him off’</td>
</tr>
<tr>
<td>Reduced self-monitoring role</td>
<td>48-50</td>
<td>‘sometimes he can be just so quiet, and you’re constantly saying you like “pardon? Can you repeat that? “’</td>
</tr>
</tbody>
</table>

### Types of comparison

| Comparison of ability                       | 78-80       | ‘I think he’s thinking, you know he’s () doing quite well, that he is () still you know making his voice heard, above other people you know?’ |
| Comparison of participation                 | 76-77       | ‘I think he, compared with a lot of the group, he’s probably a lot more outgoing’ |
| Self-consciousness                          | 83-84       | ‘I was afraid that you’re going to see people really bad, and then you’d get depressed’ |
| Comfort from comparison                     | 79-80       | ‘I think he’s thinking “ah I’m not as bad as I thought I was”’. |

### Catalyst for change

<p>| Catalyst for changes in social participation | 34-35       | ‘he’s joined quite a lot of Parkinsons things, which have () have got him out of the house’ |
| Education                                   | 217-218     | ‘I really thought it was a physical thing? You know, a shaking? I think that’s what I assumed would get worse’ |
| Adjusted spouse role                         | 123-124     | ‘it makes things harder work, you know. But you get used to it, like you get used to it’ |
|                                             | 110-113     | ‘I find that he’s a lot quieter in () like social groups. Because I was really quiet, but I could always leave him to do all the talking is necessary.’ Umm so I find it’s sort of like, you know in a family group,’ |</p>
<table>
<thead>
<tr>
<th><strong>Facing inevitability positively</strong></th>
<th>64-66</th>
<th>‘oh I think yeah (his wellbeing) that’s improved a lot. Yes, compared with, because we only really started going to these, any of these things two years ago, and compared with that, I mean he is much better you know?’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catalyst for progress</td>
<td>304--306</td>
<td>‘he sees it now as something that, you can live with it for a long time, Umm as I said, not just sitting at home waiting for uh, for it to get worse’</td>
</tr>
<tr>
<td><strong>Regaining lost identity</strong></td>
<td>105-108</td>
<td>‘because he was always prepared to you know stand up and speak in front of people, he was always prepared to do that but I think (2) maybe he’s, it’s made him realise that he can still do it’</td>
</tr>
<tr>
<td><strong>Reduced harshness of diagnosis</strong></td>
<td>261-262</td>
<td>‘I think it’s just the hope maybe? The hope that it will sort of stop things getting worse’</td>
</tr>
<tr>
<td>Active role in progress</td>
<td>86-87</td>
<td>‘even if people are bad, they can still keep doing a lot of stuff?’</td>
</tr>
<tr>
<td><strong>Mutual trust and friendship</strong></td>
<td>98-99</td>
<td>‘the same people seem to go, it’s quite a (.) you know the continuity is there, you see the same people (.) and you know, they all get on very well’</td>
</tr>
<tr>
<td><strong>Dependence</strong></td>
<td>284-286</td>
<td>‘I suppose it’s quite a good discipline, you go there (.) you get exercise done or (.) and you know, you don’t have to sit at home thinking “I should be exercising, you know?”'</td>
</tr>
</tbody>
</table>
### 7.17 Summary Table of Superordinate and Subordinate Themes

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Subordinate Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Burden</strong></td>
<td>Reduced surface burden</td>
</tr>
<tr>
<td></td>
<td>Reduced emotional dependence</td>
</tr>
<tr>
<td></td>
<td>‘Break’ from PD</td>
</tr>
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<td>Reduced self-monitoring role</td>
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<tr>
<td><strong>Types of comparison</strong></td>
<td>Comparison of ability</td>
</tr>
<tr>
<td></td>
<td>Comparison of participation</td>
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<td></td>
<td>Self-consciousness</td>
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<tr>
<td></td>
<td>Comfort from comparison</td>
</tr>
<tr>
<td></td>
<td>Heterogeneity of PD’s impact</td>
</tr>
<tr>
<td><strong>Catalyst for change</strong></td>
<td>Application of techniques in daily life</td>
</tr>
<tr>
<td></td>
<td>Catalyst for changes in social participation</td>
</tr>
<tr>
<td></td>
<td>Education</td>
</tr>
<tr>
<td></td>
<td>Adjusted spouse role</td>
</tr>
<tr>
<td><strong>Facing inevitability positively</strong></td>
<td>Catalyst for progress</td>
</tr>
<tr>
<td></td>
<td>Regaining lost identity</td>
</tr>
<tr>
<td></td>
<td>Reduced harshness of diagnosis</td>
</tr>
<tr>
<td></td>
<td>Active role in progress</td>
</tr>
<tr>
<td></td>
<td>Progress in daily life</td>
</tr>
<tr>
<td><strong>Mutual trust and friendship</strong></td>
<td>Sharing lived experiences</td>
</tr>
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<td>Group support</td>
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<td></td>
<td>Social participation</td>
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<tr>
<td></td>
<td>Camaraderie</td>
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<tr>
<td><strong>Dependence</strong></td>
<td>Dependence on group’s longevity</td>
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<td>Exercises as ‘cure’</td>
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<tr>
<td></td>
<td>Priority in spouses’ life</td>
</tr>
</tbody>
</table>
7.19 Confidentiality Checklist

Student number: 20059800                      Date: 23rd April 2018

Module Leader: Robert Mayr                  Module number: SLP 6080

Assignment: Project – ‘The spouses’ experiences of a Parkinson’s disease voice support group: An interpretative phenomenological analysis’.

Evaluate your submission and any supporting documentation, appendices etc. by answering the following questions:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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If you have answered ‘yes’ to any questions, please explain why you feel this does not constitute a breach of confidentiality in the space below: N/A
## Word Count

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<th>Total Words</th>
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<td>Introduction</td>
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<td>Literature Review</td>
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<td>Method</td>
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<td>Discussion</td>
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