**Pain in Parkinson’s disease: the lived experience**

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# **Abstract**

**Introduction:**

Pain is common in people with Parkinson’s and reported as one of the most troublesome symptoms. However, pain is under-reported and under prioritised by health-care professionals. Previous research has highlighted the prevalence and presentation of pain, but the experience of living with Parkinson’s and pain is unclear. This study aimed to develop a greater understanding of living with pain and Parkinson’s in order to guide future clinical practice.

**Methods:**

A qualitative study using interpretative phenomenological analysis was done to capture the personal experience of living with pain in a group of people with Parkinson’s. Four people with Parkinson’s who had experienced pain for at least two months were interviewed in their own home. Ethical approval was granted by the Faculty of Health and Life Sciences ethics committee, Northumbria University.

**Results**

Three master themes emerged from the interviews; psychological impact of pain, social impact of pain and disconnect between the professional and patient. It was clear that coping mechanisms differed between the participants and this was related to the amount of negative feeling towards their pain and Parkinson’s more generally. Some of the participants had found strategies to help manage the pain but none of these had been advised by a health professional and indeed a strong theme amongst all participants was the lack of attention to their pain during health care encounters.

**Discussion:**

The findings show the significant impact pain had on all aspects of the participant’s life and how pain further complicates the ability to manage the motor symptoms of Parkinson’s. The study also highlights the perception of people with Parkinson’s that pain, psychological and social well being were not discussed in interactions with health professionals.

**Conclusions:**

Awareness needs to be raised of the impact of pain on people with Parkinson’s in order to foster a more holistic approach to supporting them.

**Keywords:** Parkinson’s disease, Pain, Interviews, Patient centred care

# **Introduction**

Parkinson’s is a common neurodegenerative disorder with both motor and non-motor symptoms. Recent evidence suggests Parkinson’s degeneration begins in the dorsal motor nucleus of the vagal nerve and olfactory nucleus, followed by the lower brain stem, then the basal ganglia and forebrain and extending into the cortex. This diffuse pathology means that both dopaminergic and non-dopaminergic neural pathways are affected, resulting in numerous motor and non-motor impairments (Allen Reish and Standaert, 2015). Non-motor impairments are wide ranging and include cognitive and emotional impairments, autonomic dysfunction, sleep disorders and sensory abnormalities, such as pain. Many people with Parkinson’s suffer from chronic pain; pain is reportedly experienced by over 80% of people with Parkinson’s (Ford, 2010, Beiske et al., 2009), has been rated as one of the most troublesome symptoms (Ozturk et al., 2017), and is associated with reduced health related quality of life, greater anxiety and depression (Allen et al., 2015, Tang et al., 2008).

Understanding of the underlying mechanisms and treatments for pain remain poor. For example, several studies have reported that dopaminergic treatment improves pain in people with Parkinson’s (Brefel‐Courbon et al., 2005, Gerdelat-Mas et al., 2007), while other studies have failed to find a correlation between motor symptoms, dopaminergic medication and pain (Colloca et al., 2004). Despite evidence that the dopaminergic system is important in modulating pain perception and natural analgesia within supra-spinal striatal and extra–striatal regions, it is unclear whether in Parkinson’s dopaminergic transmission plays a role in pain processing (Berardelli et al., 2012). This is further complicated by the evidence that shows that non-motor symptoms, such as pain, are under-reported by people with Parkinson’s (Chaudhuri et al., 2010b) and are largely neglected by practitioners (Todorova et al., 2014); despite being just as debilitating as motor symptoms (Park and Stacy, 2009). It is estimated that a significant proportion of people with Parkinson’s are living with pain that has not been reported to their health care team, this is not highlighted in relevant guidelines on Parkinsonian management (Zesiewicz et al., 2010, Stewart, 2007), which limits therapeutic interventions and treatment.

There are many different forms of pain experienced by people with Parkinson’s, recognition of the particular pain disorder and relationship to dopaminergic therapy may lead to selection of the most appropriate treatment and management strategy. For example; Ha and Jankovic (2012) described musculoskeletal, dystonic, radicular – neuropathic, central, and akathitic (an uncomfortable feeling of restlessness) pain or discomfort. To deal with this complexity a multidisciplinary patient-centred approach to pain management in Parkinson’s is suggested (Fil et al., 2013), but appears to be lacking. Understanding the experience of pain from the perspective of the person living with Parkinson’s is therefore imperative (Chaudhuri et al., 2010a).

In wider chronic pain literature the importance of a person-centred approach to pain management is advocated (Peres and Lucchetti, 2010), due to the broad range of associated issues (i.e. activity limitations, depression, anxiety disorders, decreased social role, fatigue, greater strain on relationships and reduced quality of life). Given that these associations with chronic pain echo the non-motor symptoms of Parkinson’s, it is vital that clinicians acknowledge the possibility of chronic pain in Parkinson’s as a potential contributor to function and psychosocial difficulties. Many models of a person-centred approach to chronic pain management exist but are less embedded in practice with people with Parkinson’s.

This study aimed to develop a greater understanding of living with pain and Parkinson’s in order to guide health care professionals future practice. Whilst qualitative studies have become prominent in relation to Parkinson’s, they remain underrepresented within the literature. Stern (1990) pointed out that with Parkinson’s “each patient is a law unto himself”, with each experiencing unique problems. This study has been informed by an interpretative phenomenological analysis (IPA) approach to explore and capture the essence of the personal experiences of pain in four individuals with Parkinson’s. Attempts to understand what it is like to live with chronic pain secondary to a neurodegenerative condition in all its social and personal complexity are made. This was to allow an in-depth look at what effect pain has on the lives of people living with Parkinson’s.

# **Methods**

IPA allows rigorous exploration of idiographic subjective experiences and, more specifically, social cognitions (Smith et al., 2009) and enables fine-grained and contextual analyses of the phenomenon under investigation (Biggerstaff and Thompson, 2008). IPA combines a dedication to understanding the ‘lived’ experience of the participant with a belief that to achieve such understanding requires interpretive work on the part of the researcher, and offers a systematic approach to doing this (Smith, 2008). IPA is particularly useful where topic under study is dynamic, contextual and subjective, relatively under-studied and where issues relating to identity, the self and sense-making are important (Smith, 2003).

## **Participants**

This study involved four participants who were recruited following informed consent procedures from two local branches of the Parkinson’s disease society of the United Kingdom (Parkinson’s UK). Two male and two female participants were included, all had moderately severe Parkinson’s disease and were diagnosed more than 5 years before the study. The small sample size was due to the limited time and resource available for the study, therefore this study must be viewed as an initial exploration of the issues. Participants were included if they had a diagnosis of Parkinson’s disease and experienced pain/discomfort for a minimum of two months prior to the study. Exclusion criteria were inability to complete an interview and any hearing impairment or disability that affected verbal communication. There was no upper or lower age limit. Ethical approval was obtained from a Northumbria University Research Ethics Committee.

## **Data collection/interview**

Data were collected via semi-structured interviews (approx. 1 hour), held at each participants home with added input of photography/art work brought to interview by each participant if they wished. Participants were invited to use photography of objects/places that they felt represented their experience of living and coping with pain and Parkinson’s to complement the interview if they wished. The discussion around the images was included in the analysis but no separate analysis of the images was undertaken. Only one participant brought photographs to their interview. The semi-structured interviews consisted of open ended questions, designed to guide participants towards consideration of their life with pain as a person with PD. The interviews allowed flexibility to encompass individual accounts of their pain experience and other issues significant to them.

## **Data analysis**

Each interview was transcribed verbatim by the researcher (DT) within two weeks of the interview date. Participant codes rather than names were used during the transcription process to maintain anonymity and for further protection of confidentiality we have assigned a pseudonym to each participant. Data was stored on a secure server, separate to any identifying material. The data analysis was conducted in a four stage process, as follows;

***Stage one: first encounter with the text***

Each recording was transcribed verbatim with two large margins to the right for note-taking. Notations included pseudonyms for participants and third parties. The researcher listened to the recording and repeatedly re-read the transcripts to familiarise themselves with the content. During this phase the researcher made notes of any thoughts, observations or reflections that occurred whilst reading the text. These notes were recorded in the first margin.

***Stage two: preliminary themes identified***

The researcher re-read the notes and text and from this identified themes that captured the essential characteristics of the text. If analysis indicated themes disparate from earlier transcripts, the researcher revisited the earlier transcripts to ensure there were no misunderstandings of earlier texts before noting the hypothesis of a contrasting theme.

**Stage three: grouping themes together as clusters**

Themes from all the transcripts were listed on a separate page and collated into ordinate and master themes with a view to creating hierarchy of themes. Each subtheme was checked for fittingness by examining its consistency with the rest of the data. To enhance trustworthiness and credibility, data workshops were conducted with a second researcher (KB) at each stage to discuss the emerging themes and ensure they arose from the data (Shenton, 2004).

**Stage four: tabulating themes in a summary table**

A table was produced that listed the hierarchy of themes. The final themes were sent to an independent external source who has experience in the use of IPA. The researcher considered whether the themes derived were grounded in the text, namely whether themes are permissible based on the quotations marked as evidence by the lead researcher, whilst in the context of the transcript as a whole. This will ensure any biases on behalf of the lead researcher were not over emphasized in theme development.

The phenomenological nature of IPA enquiry necessitates the researcher (DT) to describe and interpret. Examination of the text at the interpretative level attuned the research to its epistemological underpinnings. This level of interpretation involved examining the participant’s use of social comparison, metaphor, shift in temporal descriptions within the text and also used psychological concepts (Smith, 2004). Thus, the researcher formed interpretative meaning based on what the participant described. The researcher came to the interpretation process as a physiotherapist and therefore is aware of the possible effect on the interpretation process.

# **Results**

For the purpose of this paper only the over-riding themes were presented, however they do represent the majority of the interview content. All the open ended questions in the interview process were in relation to pain, however all of the participants spoke of the Parkinson’s experience at times not only their experience of pain. This highlights the complex and entangled nature of pain for a people with Parkinson’s.

Table 1 demonstrates the three master and four ordinate themes that were identified from the semi-structured interviews with the participants (n=4). The two master themes had ordinate themes emerge within them and the final theme was overwhelmingly strong from all four participants accounts.

## **Psychological Impact of Pain**

### **Despair and Despondency**

Tom\* and Helen\* briefly mentioned the negative thoughts and low mood they experienced in the past, both John\* and Barbara\* spoke of hopelessness and suffering in the present tense. There were powerful statements made in relation to suicidal thoughts when the participants’ pain reached unbearable levels. Although the participants were referring to having these thoughts in the past, in line with our ethical approval, the researcher followed this up by ensuring they had access to appropriate support and were aware of the importance of accessing this support in such circumstances as well as signposting to local support networks.

**Tom: “***This is for your ears only and not Michelle’s, I’ve had thoughts in the past of suicide, it’s been that bad...I mean pains just been horrendous***.”**

**Barbara: “***I feel as if you know something’s going to snap or burst and it just sort of finishes you really, it’s so severe...Like yesterday was dreadful. I felt like shooting myself.”*

Some participants portrayed emotions of self-pity and despondency that was interpreted as feeling victim to the pain. All participants discussed being depressed or taking anti-depressant medication during the interviews.

**Helen: “***I’ve been down, you do feel “why me” sort of.”*

**John: “***I feel sorry for myself I suppose, sorry for me and a bit angry because I think, well you know, what’ve I done to deserve this?”*

**(b) Coping and Acceptance**

Each participant alluded to forcing themselves to control their physical being rather than the pain consuming them. There was a sense that the battle within participants was the attempt to overcome their pain, accept it and remain in control of their life. Participants detailed examples of their thought processes. It was considered that a contrast was evident between participants in the context of this theme.

Tom and Helen appeared to have found acceptance living with pain secondary to Parkinson’s. They both discussed the idea of forcing ‘self’ to continue with activities and not resign to the pain. Both participants quoted the phrase “mind over matter” on several occasions throughout their interview.

**Tom: “***It’s either force your body to go on and do something or stand there sit and wait for hours and then it’s like running a race the lines there you know if you put that little bit of effort in, bit more to get where you want to go and that’s how I deal with things every day, bit more effort, push it and I find I get a lot more things done.”*

**Tom: “***I think if you can accept pain and get on with life as bad as its going to be than least you’ve got something to look forward too.”*

**Helen: “***It’s strange thing, mind over matter I suppose might be it.”*

**Helen: “***I thought I’ve got a bit of pain in my back and what have you, and I thought go on there’s some roses need pruning...I felt more alive then.”*

However, this was in contrast to John and Barbara’s view of life. These participants perceived their pain to be consuming them and causing them to lose hope. John and Barbara do not appear to have found the acceptance and positive mind frame that Helen and Tom have achieved. The despair that John and Barbara demonstrate is not surprising considering the negative psychological state evident from both participants’ accounts. Tom felt he has gone through the cycle of despair that Barbara and John portray, and felt a positive attitude and acceptance of pain was the answer to escaping the negative cycle and continue with life.

**Barbara: “***I was very optimistic before the pain started but since the pain started it’s been quite hard.”*

**Barbara: “***I mean this one is so painful at the minute I could scream.”*

**John:** *“I’ve never believed in giving in to anything but just recently I’ve been thinking that it’s starting to be so wearing.”*

All four participants’ coping strategies varied within the four accounts. Coping strategies were seen as very personal to the participants as individuals and needed to be flexible depending on the severity of their pain which fluctuated on a daily basis. Tom and Helen valued exercise and heat as self-management strategies, they considered that activity was what they needed. They also alluded to exercise acting as a distraction, although they may have to force themselves (as mentioned in previous theme) to overcome pain to exercise initially, in the long term their experience was that exercise and activity was beneficial and a source of pain relief.

**Tom: “***I get out on the bike as well but I find it alright, my legs ache like hell afterwards but I don’t mind, keeps you bit fitter keeps you mobile that’s what I need.”*

**Helen: “***So I believe that keeping going and doing exercise is the way to go… I think the more I do the better I’m going to be because obviously if I feel I’m doing nothing and sit in the house not moving not doing anything that’s going to make my pain worse isn’t it.***”**

**Helen: “***I got the blanket which goes over you and it heats your neck, it does give you relief, it does help.”*

**Tom: “***It does hot and cold makes a difference, I think and cold does make things a lot worse. Heat warms the muscles so obviously you don’t get as much aches and pains.”*

Continuing the thread of contrast between participants, John and Barbara did not discuss any management strategy that gave them relief. In Barbara’s situation the lack of internal coping is evident; she has not tried any interventions or self-management strategies other than stretching, which she feels doesn’t work.

**Barbara: “***I’ve tried sort of tightening your muscles up and slacking letting them go, but that’s really all I’ve tried. I haven’t tried anything else.”*

Barbara and John’s defeatist attitudes are portrayed in the following quotes that were felt to allude to a lack of motivation.

**Barbara: “***I couldn’t I know I couldn’t (cycle/walk). I just haven’t got the strength”*

**John: “***It’s not worth exercising if you’re actually whacked out before you do them”*

Similarly, the following quotes also provided evidence of self-management strategies within the people with Parkinson’s.

**John: “***When I sit down I get it and when I stand up it relieves it (the pain)”*

**Barbara: “***Out in public I’m much better at dealing with it then...because I think it must sort of take your mind off it…but I can cope with it better when I’m with a lot of people”*

**Tom: “***I’d close my eyes, take a deep breath and just let the air out slowly and it controls your body, it’s like a mind over matter sort of thing… I figured that out myself”*

## **Social Impact of Pain**

### **(a) Participation Loss**

Pain was viewed as causing or contributing to isolation. Participants’ considerations of their experience of pain ultimately lead to descriptions of exclusion and desolation. This lead to an interpretation of the participant’s losing their participation in life

**Barbara: “***I hate being stuck at home…but lately (since the pain started) we’ve been in a lot more”*

**John: “***Oh well Liz and I our social life is just about non-existent…one thing we used to like to do was go out with our friends and have a meal but I can’t sit at the table*

**John:** *You can just see your life getting smaller all the time, you know?”*

All participants appeared to experience sleep deprivation due to pain which had implications of pain dictating their daily routine. The social isolation was viewed as a contributing factor to participant’s poor psychological well-being.

**Tom: “***Nights the cramps come on that’s when the cramps decide to ache…and it’s so painful you know it’s time to get up”*

**Helen: “***It’s so unpredictable what your pain is going to be like, that’s the thing you can’t plan ahead of time”*

###  **(b) Relationship Strains**

The effect of both the participant’s pain and Parkinson’s had on their relationship with family and spouse appeared a common thread through all four interviews. It was interpreted that participants felt they were a burden on their carer, who was their spouse in three out of four cases. It appeared participants sympathised with the hardship their families live through because of them.

**Tom: “***It’s been really hard for her as well (Michelle) …she’s been through it all and she stuck by us and it’s not easy living with people with Pain***”**

**John: “***They’ve made her (Liz) my carer in their mind and she doesn’t want to be my carer, which I can understand because why she should? If they’ve got somebody whose ill looking after somebody else, she’s ill and I’m ill as well”*

Participants also discussed the guilt they feel when their suffering affects their spouse. As discussed in previous themes the result of living with pain as well as Parkinson’s not only effects the participant but also the care givers. It has been demonstrated in previous themes how John feels his social life with his wife (Liz) is non-existent and how Tom hides his past suicidal thoughts from his wife, Michelle. Barbara also details the guilt she feels for burdening her husband Harvey with her emotions and pain, creating the perceived need to conceal her experiences from him.

**Barbara: “***Harvey heard me crying downstairs you see, and that was how he came down. Usually I can hide it from him on a morning you know?...I just feel guilty, guilty really because he gets so upset”*

**Barbara: “***Harveys not very good at discussing things, he doesn’t like to think about it. He likes to think it’s as if you don’t talk about it it will go away”*

**Helen: “***I don’t think Shane wants to think of me in pain”*

## **Disconnect Between Professional and Patient**

This theme evolved in different forms from the interpretations of all four participants and appeared to effect all aspects of their pain experience. Participants accounts alluded to a lack of holistic care, they felt treated as symptoms rather than a person with biopsychosocial needs. Participants felt medical staff did not have time for their needs other than medication adjustments in relation to their symptoms. Barbara felt her psychosocial well-being was not of concern to her Parkinson’s specialist. John felt his pain was not understood by medical staff.

**Barbara: “***They ask about your symptoms, how you’re managing with your tablets and so forth but I don’t think they would ever think about asking you how you felt”*

**John: “***I don’t think they do (understand his pain), I’ve never been asked to explain it, nobody’s ever asked me like you’ve just asked me now, to explain it and they’re professionals”*

**Helen:** *“I now think my own specialist was , he never ever said any advice about what you could do to help yourself or anything like that, he never had the time I don’t think”*

The interpretation of these accounts led the researcher to conclude these participants did not feel they were the focus of their care. No participant alluded to the existence of a rapport with their Parkinson’s specialist or doctors. It appeared there was a lack of trust and understanding between the participants and some health care professionals involved in their care.

**Helen:** *“Then all of a sudden I got all this pain in my neck…I found out I was taking this ropinarol which was the wrong thing…I feel disappointed at the fact the specialist gave me the wrong drug but what can you do, it was a mistake”*

**Helen:** *“I could always ask the specialist but then again he probably wouldn’t know”*

**John: “***I think they’ve done as many scans as they possibly can on somebody and they still don’t know”*

The participants described a lack of external support from medical and therapeutic interventions. it was outside the scope of the study to explore this from the health professional’s perspective. The lack of understanding about the cause of their pain led to participants having their own perception of the reasons for their pain. This appeared to add to the psychological impact of pain. This was viewed as a contributing factor to the participants questioning the need for the medication prescribed to them by the Parkinson’s specialist/doctors involved.

**Tom:** *(when asked does specialist give advice or guidance about ache and stiffness) “no not really, I mean  doctor Nathan the neurologist , he has given me dispersible one a night and one in the morning, that’s all it is”*

**Barbara:** “*I saw Doctor Joe and all he did was look at one of my tablets to see how that would help”*

***Barbara:*** *“Thinking about it, it’s when I come to the end of a dose of tablets, it’s like when the dose is wearing off, it starts to feel as if something isn’t getting enough of something”*

**Helen: “***It’s the medication causing the problems”*

A disconnect between the medical team, health care professionals and people with Parkinson’s emerged from the participants accounts. It is evident there is a lack of interplay between external support (medication/symptom management) and internal support (coping and self management strategies).

# **Discussion**

This study aimed to develop a greater understanding of living with pain and Parkinson’s in order to guide health care professionals future practice. Three key master themes and four ordinate themes emerged from the participant interview accounts. The master theme of ‘Psychological Impact of Pain’ had ordinate themes of ‘Despair and Despondency’ and ‘Coping’ and ‘Acceptance’. The master theme of ‘Social Impact of Pain’ had ordinate themes of ‘Participation Loss’ and ‘Relationship Strains’. The third master theme that emerged was ‘Disconnect between Professional and Patient’. For clarity we have used the master themes to discuss the study findings.

The master and ordinate themes indicated that pain affected psychological and social aspects of the lives of people with Parkinson’s. The participants described both psychological and active coping strategies to deal with the pain. It was the experience of these participants that the effect of pain and coping with pain was not managed or assessed by healthcare professionals involved in their disease management. For this reason they found internal support and coping strategies to deal with their pain. It was the interpretation of the authors that a need for a holistic and patient-centred approach to managing pain in people with Parkinson’s is required.

## **Psychological Impact of Pain**

*Despair and Despondency*

Feelings of suffering, despair and anxiety were present when pain was particularly severe in people with Parkinson’s. For example, statements in relation to suicidal thoughts were made when participants’ referred to time-points when they felt their pain reached unbearable levels. Depressed mood is a common and often debilitating emotional state that affects the pain experience (Linton and Bergbom, 2011). Depression and anxiety in Parkinson’s are well documented, and influence pain severity and disability ratings (Rana et al., 2013). Ford (2010) described depression as a common symptom in Parkinson’s that may contribute to the complexity of chronic pain syndrome. The theme of ‘despair and despondency’ that emerged from participant’s accounts echoed the above research findings. Suicidality, including suicidal ideation, suicide attempts and suicide completion has been repeatedly identified among people with chronic pain (Kostić et al., 2010). Possible mechanisms affecting increased risk for people living with chronic pain include the role of mental health syndromes (e.g. depression), the role of variables associated with chronic illness and suffering, and even the role of socioeconomic variables associated with pain-related disability. Evidence regarding suicidal thoughts related to pain in people with Parkinson’s is currently limited, but they may be influenced by the depressive symptoms associated with the disease.

*Coping and Acceptance*

Strategies are used to manage pain and its impact, also known as coping (Peres and Lucchetti, 2010). The participants of this study spoke of different forms of coping; psychological coping and active coping. Regarding psychological coping there was a sense that the battle within participants was the attempt to overcome their pain, accept it and remain in control of their life. Contrast between participants was evident, some were viewed to have found acceptance living with pain secondary to Parkinson’s quoting A “mind over matter” approach. Whereas others perceived their pain to be all consuming and causing them to lose hope. Using Dubouloz et al. (2010) three stage model of transformation when living with a chronic illness, we can compare participants coping psychologically with the final stage of transformation, integration of new ways of being. However, others remain unable to move past the suffering and initial reaction stage. In McCracken et al. (2004) acceptance of pain was associated with less pain, less disability, less depression, less pain-related anxiety, higher daily uptime and better work status. Considering our sample lives with multiple factors that predispose them to depression, it is not surprising that finding their way through the coping process is difficult.

Exercise, heat and self-management were active coping strategies identified from the participant interviews. Exercise served as distraction from the pain, although they had to force themselves to overcome pain to exercise initially. Overall the experience of exercise and physical activity discovered independently by the participants was beneficial and a source of pain relief. Echoing the thread of contrast between participants, those who appeared to be coping psychologically had devised self-management strategies for painful periods whereas other participants had not tried any management techniques or advice given to them as they felt it was hopeless. Evidence supports exercise as being beneficial with regards to physical functioning, health-related quality of life, strength, balance and gait speed for people with Parkinson’s (Goodwin et al., 2008, Allen et al., 2015). People with pain who believe that they are capable of exercising regularly may be more likely to initiate and persist in a regular exercise program. However, this belief appeared to prove difficult for some participants in the current study, as they felt exercise was beyond their capabilities due to the severity of their pain and their Parkinson’s related mobility impairments. There is a gap in the current evidence base around the specific benefits or necessary dose and style of exercise best suited to addressing pain in people with Parkinson’s.

For people living with long term conditions, such as Parkinson’s, self-management can become a more fundamental part of their everyday lives, to ensure independence, self-worth and the ability to lead as active a life as possible (Davies, 2010). Two of our participants show signs of empowering themselves through self-management. This affords them a certain level of control of their pain which appears to improve their coping.

## **Social Impact of Pain**

*Participation Loss*

The social impact of pain was viewed as causing or contributing to reduced participation in life. Participation was lost due to isolation, exclusion and sleep deprivation. Participants’ considerations of their experience of pain ultimately lead to descriptions of exclusion. For example, sleep deprivation due to pain impacted their daily routine by limiting time spent socialising. Social isolation was viewed as a contributing factor to poor psychological wellbeing, which agrees with previous research that has stated that social isolation and exclusion poses numerous immediate threats to physical and mental health (Bernstein and Claypool, 2012). Observations have been made that demonstrate pain and social exclusion are inherently intertwined in human phenomenological experiences (Kowal et al., 2012). These links are evident in this study as the participant’s attempted to make sense of their pain experience secondary to their Parkinson’s. Although no specific evidence exists in Parkinson’s, in a study of pain interference in Multiple Sclerosis, results indicated a significant relationship between depression symptom severity and the levels of pain interference with daily life (Osborne et al., 2007). This was similar to the current study which had the strong theme of psychological distress with depression and the levels to which pain affected their daily life viewed as interlinked. Their appeared to a cyclic pattern in addition to the general progressive nature of Parkinson’s; pain caused isolation which exacerbated low mood resulting in an increased pain experience.

*Relationship Strains*

The participants of this study alluded to the pain and its effects putting a strain on their relationships with family or spouse. It was interpreted the participants felt a burden to their carer, who was their spouse in three out of four cases. Self-perceived burden (SPB) and perceived burdensomeness have been identified as putative causes of the desire for suicide (Kostić et al., 2010). Given the high rates of depression and suicidality in chronic pain, SPB may be relevant to the association between both variables (Kowal et al., 2012). Although SPB was not interpreted in this study as a direct cause of participant depression, it was viewed as a contributing factor. It appears an interplay exists between the psychosocial well-being of participant’s creating strain on their relationships, and the new relationship dynamic due to pain, affecting the participants psychosocial wellbeing.

## **Disconnect Between Professional and Patient**

Lacking a patient centred care approach, was overwhelmingly noted from the interpretations of all participants and it appeared to affect all aspects of their pain experience. Participants described feeling a burden to medical staff, and suggested a biomedical approach was often used. Time was made for adjustment of medications but patients did not feel their pain or psychological wellbeing was understood or given attention by the medical staff. It was evident from the participants of this study that the conceptual framework of care they were treated in had an overwhelming effect on their experience of pain. It appears from our interpretations the physical, psychological and social effects of Parkinson’s are heightened by the presence of pain. Participants felt medical staff could not give them answers to the cause of their pain and therefore self-diagnosed the pain as a side effect of the Parkinson’s medication “a necessary evil”. Another participant was convinced she had a brain tumour causing her pain. These fears and anxieties were not addressed or discussed by medical staff with participants. The authors interpreted this fear of the unknown as affecting the psychological and active coping of the participants with their pain. In a cross sectional survey it was found that 50% of Parkinson’s patients with pain did not receive any treatment, either with pharmacotherapy or physiotherapy (Chaudhuri et al., 2011, Chaudhuri et al., 2010a). Increased awareness of these symptoms may allow for more comprehensive patient evaluation and management.

The biopsychosocial paradigm conceptualises the medical condition as a manifestation of the complex interaction among physiological, psychological and social factor (Theodore et al., 2008). Characteristics of treatment modalities for pain should be interdisciplinary, and based on the biopsychosocial model by recognising that pain is a complex and multidimensional phenomenon with various interacting components. As depicted in Figure 2 the participants of this study were missing a multidisciplinary approach where internal and external supports overlap to manage pain in Parkinson’s. Two out of four participants had never received physiotherapy for their Parkinson’s or pain, and appeared unaware of the potential role of physiotherapy in managing pain or how they would access it. This lack of inclusion of pain as a part of a multidisciplinary approach to disease management has not been recognised previously in Parkinson’s, but has been noted in other co-morbid groups, such as obese individuals (Cooper et al., 2017) or people with Chronic Obstructive Pulmonary Disorder (Harrison et al., 2017).

Health professionals are trained to develop a hypothesis about the genesis and maintenance of pain (Roth et al., 2012). However families and sufferers develop their own theories about the pain, often developed and honed through previous experiences and in conversation with those around them. Often both party’s understandings are disparate. In order to bridge the gap between professional understanding and family/patient understanding, collaboration between the health professional and patient must be enhanced. Better communication and mutual understanding pave the way (Gifford, 2013).

## **Limitations**

The researcher recognises the limitations of this study due to it’s small sample size (n=4), however this is not uncommon within IPA studies that focus on depth of experience rather than spread of experiences. We did not use an objective measure of pain severity or the type of pain, which reduces the ability to compare to other studies. Our study did not have the scope for a long-term follow up therefore only represents a snapshot of the participants pain experience. Future studies are required to examine long-term pain in Parkinson’s and the effects of potential interventions, such as exercise or pharma-logical treatments.

## **Clinical Implications**

People with Parkinson’s report that they experience high levels of pain, which influences both psychological and social aspects of their lives, such as depression severity and participation loss. All clinicians, medical and allied health professionals alike, are encouraged to maintain a heightened awareness of the impact pain has on the psychological and social aspects of life for people with Parkinson’s. This study highlights gaps in multidisciplinary support available to people with Parkinson’s for their pain and also the lack of a patient centred care approach to managing pain in Parkinson’s. The findings encourage all clinicians to adopt a patient centred care approach to the comprehensive management of pain in Parkinson’s.

# **Conclusions**

This study has shown the impact pain has on the psychosocial wellbeing of people with Parkinson’s, as well as the far reaching effects the model of care implemented by clinicians can have on their pain experience. As the current study has demonstrated pain had a large psychosocial impact on these four participants, this demonstrates the need for patient centred care informed by a biopsychosocial approach. Unfortunately the existence of patient centred care or a multidisciplinary support framework was not evident from the participant’s of this studies experiences. Consider these participant experiences of pain in the context of the evidence encouraging a patient centred and holistic approach to Parkinson’s These experiences further strengthen the need for a biopsychosocial and multidisciplinary approach to caring and supporting people with pain and Parkinson’s.

# **Conflict of Interest**

There were no conflicts of interest in this study.

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**Table 1 - Emergent Themes**

|  |  |
| --- | --- |
| **Master Themes** | **Ordinate Themes** |
| Psychological impact of pain | 1. Despair and Despondency
2. Coping and Acceptance
 |
| Social Impact of Pain | (a) Participation Loss(b) Relationship Strains |
| Disconnect Between Professional and Patient |  |

**Figure 1 - Psychological and Social impact of pain for people with Parkinson’s and their cause-effect relationship**

**Figure 2 - Different types of support participants used and the call for them to overlap.** *[The experience of the participants in this study appeared to demonstrate the lack of interaction and overlap between external and internal support system]*