

“What are the factors that influence participation in physical activity for people with Parkinson’s Disease living in Western New South Wales”



Health
Western NSW
Local Health District



**HEALTH
EDUCATION
& TRAINING**



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The photo on page one was taken by the author as she was driving through Western NSW LHD. It has not been photo shopped. It piqued her interest and reflected the resilience of people living in rural areas.

Acknowledgements:

The author has been working with people with Parkinson's Disease for 20 years, and would like to thank all those people for sharing their journey, throughout the various stages of their lives. This has led to a desire to want to know more, and to look into service development for people to live a better quality of life with their disease.

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Abbreviations

ADL	Activities of daily living.
HETI	Health Education and Training Institute
PD	Parkinson's Disease
PWPD	Person/People with Parkinson's Disease
QOL	Quality of life
RRCBP	Rural Research Capacity Building Project
WNSWLHD	Western New South Wales Local Health District

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ABSTRACT

The factors that influence engagement with physical activity for people living with Parkinson's Disease in Western NSW – a Qualitative Descriptive study.

BACKGROUND: Parkinson's Disease (PD) is a progressive neurological disease affecting 1% of the population over 65 years of age, with the incidence increasing with age. There is no cure for this disease, and effective management strategies must be put in place to empower those living with this disease to lead a better quality of life (QOL).

Although the knowledge base about the positive benefits of physical activity for people with PD is growing, the number of people living with PD who actively engage in physical activities remains low. Therefore, the aim of this study is to investigate, in a rural region, what factors may influence the decision for someone who is diagnosed with PD to participate in physical activities or not.

METHOD: A qualitative descriptive study was designed to capture information from participants via face-to-face interviews. Geographical areas of Parkes, Forbes and Cowra were chosen as the study sites because they fit the Modified Monash Model classification of rural and remote (level 4-7).

Recruitment involved the distribution of informational flyers and interested people contacted the researcher and were sent a Participant Information Sheet (PIS) and consent form. Once the consent form was received back an appointment was made for an interview in their home, or location of their choice. Thirteen interviews were conducted in this qualitative study. A cut and paste method was used to group themes, followed by a descriptive analysis.

RESULTS: The data analysis from this study suggests that a person's attitude and emotional response towards physical changes, managing loss, and their understanding of the role of exercise within the complex nature of their PD influence participation in physical activity. Attitude is itself a multifactorial concept, which develops across the life course. Those participants who actively sought resources to influence their attitude and behaviour were more likely to participate in physical activity.

IMPLICATIONS: The results of this study may be used better inform content and planning for programmes that can meet the specific needs for people living with Parkinson's Disease in rural NSW.

EXECUTIVE SUMMARY

Implications:

- The number of people living in WNSWLHD with Parkinson's Disease is increasing due to an aging population. It is expected that in Western NSWLHD more than 55 people will be newly diagnosed with PD every year. Life expectancy living with PD ranges from 10-20 years, with a high burden of care as the disease progresses. People with Parkinson's Disease present to hospital at a higher rate and with longer length of stays compared with age matched individuals without PD.
- Exercises has been proven in the literature to improve quality of life years, lead to improvements in symptoms, possibly slow disease progression and reduce falls for people with Parkinson's Disease. An understanding of the importance of exercise and participation in exercise and physical activity is low.
- To meet the physical activity needs of PWPD a complex range of factors need to be taken into consideration including acceptance of change, information exchange and perception of exercise and physical activity.

Recommendations:

- Greater consideration needs to be given to the management of non-motor symptoms of PD in conjunction with the typical motor symptoms. Attitude towards, and understanding of, exercise and physical activity are determining factors of participation.
- That a coordinated approach be taken to managing the health needs of people with PD, including early intervention, community education and acute care management with care coordination.
- Currently service mapping is occurring within the LHD, and there is a strong push to employ a "Parkinson's Nurse" to be embedded within WNSWLHD. Both a nursing model and a multidisciplinary model of care need to be considered when developing a service delivery model to support people living with Parkinson's Disease in WNSLHD.

Background:

Parkinson's Disease (PD) is a progressive neurological disease affecting 1% of people over the age of 65 in Australia. The prevalence of PD is quoted as being 160-300/100 000, (DUNCAN; ROSITANO, 2011) which equates to 443-832 people living with PD in WNSWLHD. This number is expected to grow. After diagnosis, the life expectancy for people is variable, with many studies and doctors referring to a life expectancy of 10 years. In clinical practice, some people live with PD for 15-20 years, depending upon the severity of the progression of the disease.

Symptoms of PD include tremor, slowness of movement, stiffness of movement, and impaired posture and balance. There are many other 'non-motor' problems including anxiety, depression, constipation, hallucinations and cognitive decline. Diagnosis is often prolonged due to the complexity of symptoms that are often difficult to describe in the early stages. Burden of disease and carer stress are quite prevalent with PD, especially as the disease progresses. Lobbying is quite active in New South Wales to employ a "Parkinson's Nurse" in every rural Local Health District (LHD), with the recommended model being proposed that of a nursing position being embedded within the LHD. Current evidence suggests that high intensity, high amplitude exercise can result in neuroprotection, and may even slow the progression of the disease. (FRAZZITTA; MAESTRI; BERTOTTI; RIBOLDAZZI *et al.*, 2015; HIRSCH; FARLEY, 2009) Others show a significant reduction in symptoms, increased walking speed, and a reduction in falls.(CANNING; PAUL; NIEUWBOER, 2014). There are currently no other known pharmacological or non-pharmacological interventions that can achieve these changes.

Relatively less research evidence is available about the factors that influence why a person might choose to participate in exercise specifically to manage their PD. Evidence exists that doing any form of physical activity is better than none, however what influences a person with PD to change their behaviour and participate in physical activity is not well understood.

This study:

A qualitative research project was undertaken using qualitative descriptive methodology. Semi-structured interviews were conducted with people living in WNSWLHD who have PD, living in towns that fitted into the criteria set as being Modified Monash Model level 4-7 representing rural and remote classification of remote, with a population of between 5 000-15 000. They were also towns in which the researcher was not known, to avoid any bias in the interviews. Parkes, Forbes and Cowra were the sites.

Each interview was conducted so that the person could speak freely about their PD history, from pre diagnosis through to current management. The interview included questions exploring self management, their perception and experience of physical activity and exercise, their perception of what is available to help them manage their symptoms, and what services they would like available to meet their management needs. The interviews were audio recorded with consent, and then transcribed using a transcription service. A total of 13 interviews were conducted, a transcription service was used and the deidentified data analysed using cut and paste coding and descriptive thematic analysis.

Findings:

People living with PD in WNSWLHD have inconsistent access to information and services to meet their chronic health needs. Factors

that influenced participation in exercise and physical activity could be themed as information exchange, identity, acceptance to change, grief and loss, perception of exercise and psychological support.

The data analysis from this study suggests that a person's attitude and emotional response towards physical changes, managing loss, and understanding of the role of exercise within the complex nature of their PD influences participation in physical activity. Attitude is itself a multifactorial concept, which develops across the life course. Those participants who actively sought information, about disease management and psychological support, to influence their attitude and behaviour were more likely to participate in physical activity.

A very common thread for many participants was their perception that doing their activities of daily living was enough. Conversations with medical professionals were often non-specific about physical activity. Participants reported that when they were being told they are 'doing well' there was no indication that they should also be doing more. This interpretation reinforces the attitude of participants who honestly believed that the exercise and physical activity that they were doing is enough. Participants reported avoiding tasks that would lead to fatigue or that were perceived as difficult. This is in contrast to the evidence in the literature regarding intensity of exercise. The only exercise classes available to PWPD in the geographic areas of the study were classes targeted for people with chronic cardiorespiratory illnesses. Those who attended these classes were very grateful to have access to some form of structured exercise, and face to face contact with health professionals. This contact assisted and promoted participation in physical activity.

The data collected in this study supports the need to recognise the themes of identity, grief and loss and information exchange as factors to consider when planning and designing health services for people living with Parkinson's Disease in WNSLHD.

INTRODUCTION

Parkinson's Disease (PD) is a neurodegenerative disease that people live with for up to and beyond 20 years, depending on the disease progression and comorbidities. Throughout these years, PWPD have

many challenges relating to motor and non-motor symptoms of the disease. For many people, lack of understanding from others, and lack of information at the time it is needed, leads to isolation and less than ideal chronic disease management.

For some people, their first encounter with the health system is at a time when their disease has progressed leading to falls, injury and hospitalisation. As a health professional, it is understood that chronic care disease management can help add quality of life (QOL) for people, encourage better partnerships with consumers and the health care system, and reduce the adverse health effects and isolation that often accompanies social withdrawal.

As a Physiotherapist working with people living with PD for over 20 years, I began to notice that what I considered best practice, was not what PWP had heard, understood or were practicing themselves. This then led me to question why more PWP did not engage with or participate in physical activity to help improve their QOL living with PD.

Work is currently quite active in New South Wales to employ “Parkinson’s Nurses” in rural areas, with the recommended model being that of the position being embedded within the Local Health District (BRAMBLE; CARROLL; ROSSITER, 2018). Parkinson’s NSW is actively lobbying state parliament for funding for these new positions, and discussions are happening at a local level within many LHD’s exploring the services available for PWP, including WNSLHD.

BACKGROUND

Parkinson’s Disease is a progressive neurological disease affecting 1% of people over the age of 65 in Australia (HAYES; FUNG; KIMBER; O’SULLIVAN, 2010). The annual incidence of people being newly diagnosed is 20/100 000. In Western NSW Local health District (WNSWLHD) this equates to 55 people every year being newly diagnosed with PD. After diagnosis, the life expectancy for people is variable, with many studies and doctors referring to a life expectancy of 10 years. From the experience of many clinical practitioners, people often live with PD for 15-20 years, depending upon the severity of the progression of the disease (HELY; MORRIS; TRAFICANTE; REID *et al.*, 1999).

Symptoms of PD include tremor, slowness of movement, stiffness of movement, and impaired posture and balance (HAYES; FUNG; KIMBER; O’SULLIVAN, 2010). There are many other ‘non-motor’ problems including anxiety, depression, constipation, hallucinations and cognitive decline (O’BRIEN; CLEMSON; CANNING, 2016). Due to the complexity of symptoms which are often difficult to describe in the early stages and there being no definitive test to diagnose PD until

autopsy, it can take years to reach a diagnosis of PD. At diagnosis, people with PD are often less active than their aged matched people without PD (BENKA WALLEN; FRANZEN; NERO; HAGSTROMER, 2015). Due to the many and varied symptoms, and the complex and chronic nature of the disease, it is widely recommended that a multidisciplinary approach to management be available to people with Parkinson's Disease (PWP) (DUNCAN; ROSITANO, 2011) (FRAZZITTA; MAESTRI; BERTOTTI; RIBOLDAZZI *et al.*, 2015).

In rural areas, access to specialist services, including a Neurologist, can be inhibited due to factors including distance, limited access and long waiting list. Quality of life (QOL) outcomes for PWP in rural Australia have been shown to be lower when compared to metropolitan counterparts (DUNCAN; ROSITANO, 2011).

It is expected that a General Practitioner (GP) or a Neurologist will give the diagnosis, and explain the multifactorial disease process and its management early in the diagnostic process. The complex range of pharmacological management options often forms part of these early consultations. A diagnosis of PD is a life changing event, and it has no cure. Many people feel quite overwhelmed (DUNCAN; ROSITANO, 2011).

Although it may not be included in discussions in the diagnostic or early intervention phase, participation in exercise and other non-pharmacological modalities are important treatment options for PWP. Access to PD specific modalities of exercise, such as high intensity and amplitude focused movement is limited within WNSWLHD. There are programmes existing, predominantly targeted at falls prevention, such as Stepping On and LiFE. There are others aimed at populations with cardiac or respiratory issues, which usually take place at the local hospital. Stepping On specifically excludes people with neurodegenerative diseases such as PD. The other programmes exist to promote physical activity and wellness within the more general populations of chronically unwell people such as cardiac and pulmonary rehabilitation, and do not cater for the specific movement needs of the PWP.

People with PD have a higher number of presentations to their Emergency Department, and a higher number of falls. It is reported that 45-68% of PWP fall annually (CANNING; PAUL; NIEUWBOER, 2014; FASANO; CANNING; HAUSDORFF; LORD *et al.*, 2017). It has also been shown that people with PD had higher rate ratios for fall admissions and injury and longer median length of stay compared to other age matched people (PAUL; HARVEY; CANNING; BOUFOUS *et al.*, 2017). This is a complex and distressing manifestation of PD, one that affects their family and affects QOL.

Exercise is widely recognised an important treatment option for PWP, and research into different modalities of exercise for PD management is ongoing. Current evidence suggests that high intensity, high amplitude exercise can result in neuroprotection, and may even slow the progression of the disease (FRAZZITTA; MAESTRI; BERTOTTI; RIBOLDAZZI *et al.*, 2015; ZHOU; BARKOW; FREED, 2017). Others show a significant reduction in symptoms, increased walking speed, and a reduction in falls (FASANO; CANNING; HAUSDORFF; LORD *et al.*, 2017; MORRIS; MENZ; MCGINLEY; WATTS *et al.*, 2015).

Relatively less research evidence is available about the factors that influence why a person might choose to participate in exercise specifically to manage their PD. Evidence exists that doing any form of physical activity is better than none, however what influences a person with PD to change their behaviour and participate in physical activity is less known. (ENE; MCRAE; SCHENKMAN, 2011).

The attitude and availability of a carer can influence participation in physical activity. Apathy as a symptom of PD can inhibit motivation, and it is often a carer or support person who helps provide information and practical support with the disease management. Carer stress is high amongst the population of people with PD. Carers are required to take on an ever-increasing load over time, at a time when potentially those they are caring for are losing insight into the impacts of their disease. These caregivers are also aging themselves, often with their own health issues. Caregiver burden increases with disease duration and severity. Informal caregivers provide emotional support, give direct and daily care, often liaise with formal organisations and may also provide financial assistance (SCHULLER; VAUGHAN; WRIGHT, 2017).

Non-motor symptoms such as cognitive impairment sleep disorders, mood disorders, and autonomic dysfunction are responsible for significant morbidity. The time to reach diagnosis and also the satisfaction with the explanation of the diagnosis has been shown to have a favourable impact on the QOL of people with PD in the long term (HAYES; FUNG; KIMBER; O'SULLIVAN, 2010).

Key Words:
Parkinson's Disease
Participation
Physical Activity
Quality of life
Rural

PRIMARY

The aim of understanding what forms attitudes, beliefs and behaviours of PWP

OBJECTIVE

this study is to

towards participation in physical activity in order to inform development of services to meet physical health needs of PWPDP.

SECONDARY OBJECTIVE

1. To understand what factors may influence perceptions of physical health for PWPDP
2. To inform policy and creation of PD specific exercise programmes for people living within WNSWLHD. This may also include informing holistic 'wellness' programmes to also meet the need of timely information exchange on the many different motor and non motor symptoms that people experience.

METHOD

The current qualitative study is informed by a qualitative descriptive methodology investigating the history of people living in WNSWLHD who have PD from pre diagnosis through to current management. Of particular interest were self-management, their perception of what is available to help manage their symptoms, and what services participants would like available to meet their management needs.

Study location/site: The towns identified as recruitment sites were Parkes (postcode 2870), Forbes (postcode 2871) and Cowra (postcode 2794). These towns were chosen as they are each at least one hour drive away from the larger sites within the LHD of Dubbo, Orange and Bathurst. This was to source information from people living in a rural setting. These towns also fit into the criteria set as being Modified Monash Model level 4-7 representing rural and remote classification of remote, with a population of between 5 000-15 000. Residents in these towns did not know the researcher, to avoid any bias in the interviews.

Participants: Any adult living with a diagnosis of Idiopathic Parkinson's Disease living in WNSWLHD, in the towns of Parkes, Forbes and Cowra were included.

Recruitment approach: To recruit people in the rural communities of Parkes, Forbes and Cowra the researcher approached the Practice Managers for the Neurologists in Orange and Dubbo to assist and invite people attending treatment at their practice to participate. The staff in a neurology practice in Orange assisted recruitment by mailing an invitational flyer to individuals on their database of people living with PD in the included geographic locations. Large flyers advertising the research study were also placed on the noticeboard within the neurology practice. The mail out included an invitational flyer, participant information sheet and a postage paid return addressed envelope. This envelope was addressed to the researcher, who was unaware to whom invitations were sent.

The researcher also asked Pharmacists in the three geographic areas of Parkes, Forbes and Cowra to distribute an invitational flyer with any PD medications that were being dispensed at their pharmacy.

Number of participants: Data collection continued until data saturation was reached. At this time, the Pharmacies and neurology practice were notified and thanked for their participation, and a request made that they cease promoting recruitment to the study.

Data collection: The researcher designed the interview questions in consultation with Health Education and Training Institute mentors and qualitative research experts from Charles Sturt University and University of Sydney School of Rural Health. The questions were pilot tested with three people known to have PD from the hometown of the researcher, and those results were not included in the analysis, as they did not fit the geographic criteria for inclusion.

Interested participants contacted the researcher and an agreed time and venue for the interview was arranged. Informed consent was gained verbally, and a signed consent form was then accepted as entry into the study. Interviews were audio recorded and transcribed for data analysis. Participants were not invited to review the transcribed interviews. Field notes were also kept for the purpose of researcher reflection and to contribute extra data that was collected once the recording device was stopped (PHILLIPPI; LAUDERDALE, 2018).

Data analysis: The qualitative data from deidentified transcribed interviews was analysed using a cut and paste method, followed by an inductive thematic analysis approach. The interview transcriptions were read and re-read, and themes relating to exercise and participation were grouped together. Field notes that had been taken at the conclusion of every interview were added to the data for analysis. The emerging themes were narrowed down into larger overarching themes. Key themes and ideas were drawn from the data and these were compared and contrasted across data from different participants.

Ethics: Greater Western Human Research Ethics Committee approval was granted on 17/10/2018 for the project 2018/ETH00328.

FINDINGS

Results: Reading of transcripts and first level analysis was performed after 10 interviews were conducted. Data saturation was reached when no new themes were identified in the data. Thirteen interviews in total

were conducted and analysed. Two people contacted the researcher after the interview period had closed, and were advised that their input could not be taken or included.

All interviews except one were conducted in the person's home. One interview was conducted in a public library, the location chosen by the participant.

All participants reported engaging in the study from either the pharmacy flyer or via the direct mail out invitation. Snowballing was encouraged but did not occur.

Five people participated in the interview with their carer also present and contributing to the interview. Four other people had an identified carer whom was either a spouse or close friend, however that person was not present for the interview. The remaining four people lived on their own, and did not have an identified carer.

Demographic characteristics: The age of participants varied from 64 to 84 years of age, with the average age being 73.

The time since diagnosis of PD ranged from six months to 18 years, with the average time since diagnosis being 5.6 years.

The male: female ratio of participants in this study was 77:23. This is representative of the larger population of People With Parkinson's Disease (PWPD), which is usually regarded as a ratio of 2:1 (MILLER; CRONIN - GOLOMB, 2010).

Participant demographic	n= 13
Age	Range 64-84
Time since diagnosis	6 months to 18 years
Male/Female ratio	10 males 3 female

Emerging themes:

Accepting physical change and new identity: One of the most evident themes to emerge from this study related to perception of self, self-efficacy, and how this changes during the course of the disease. Participants described how they no longer felt "normal", and they struggled with having other people understand the overwhelming complexity of how they feel, and the difficulties of movement, living with PD.

"You know, you pride yourself on what you're able to achieve, and did before. And then you ... I, I felt inadequate in what I was doing because it was just, you were different".

(Participant E)

Many people stopped telling people how they actually felt, due to a feeling that no one else "knows" how it feels to live with PD. Participants reported feeling more uncomfortable in social situations, especially when people wanted to ask after their wellbeing.

“I feel dreadful a lot of the time but I don’t tell anyone ’cause it’s not apparent that I’m like it. I don’t whinge about it because I know I don’t look unwell, I don’t look sick, but I know how I feel. What’s the point?” (Participant D)

Beliefs about one’s ability to perform has been shown to be a strong predictor of participation with exercise (ELLIS; CAVANAUGH; EARHART; FORD *et al.*, 2011). The participants in this study who chose to engage in physical activities as a part of their PD management had a belief that they could do exercise, and had health professionals encouraging and reinforcing this positive behaviour.

Slowness and an inability to do certain tasks had an impact upon self-efficacy and participation. Participants associated their identity with their work, or roles within their home and community. The participants interviewed reported being concerned about being labelled “lazy”, and expressed feelings of guilt for not contributing as they once did to their family or work environments. People interviewed were able to describe their own awareness of their changes, from what they used to be to how they are now.

Sense of identity is also challenged with a diagnosis of PD. Participants reported their sense of value of themselves is closely associated with their work, and their ability to produce an income. These participants also had a strong attitude that work = time = money. This did influence their attitude and participation in physical activity, as exercise and physical activity was not valued. A high proportion of the male participants in this study had spent their working career doing heavy, manual tasks. Their perception of identity was strongly linked to their work. When they could no longer work, they sensed no value in exercise.

Grief and loss: People who participated in the study spoke about their feelings of loss. This was described in many ways, and had many different emotions associated with it. There was an overarching sense of acceptance for most people. How people reacted and responded after this acceptance was quite different. Some people chose to attempt to “ignore” it, whereas others used it as a motivator to do as much as they could to control in some way what course their disease process may take. These responses are important considerations, as adapting to change and loss has been identified as a factor in exercise programme participation (O’BRIEN; CLEMSON; CANNING, 2016).

It was commonly reported by participants living with PD that they had to sell their farm to move into town, had their house on the market, or had moved premises because of their PD. This was also described as a loss, and people reported feeling upset that PD forced them to make a

decision they would not have otherwise made. Participants reported a sense of having no control. This sense of no control flows over into attitudes towards physical activity, as participants reported feeling helpless in being able to modify their disease outcome. When people reported feeling loss, frustration and fear for the future, without any structured advice and means of controlling their life outcomes in any small way, a sense of being resigned to their fate prevailed (ELLIS; CAVANAUGH; EARHART; FORD *et al.*, 2011). Apathy and other non-motor symptoms of PD have also been identified (O'BRIEN; CLEMSON; CANNING, 2016) as contributing factors to participation in exercise. This study also revealed many participants for whom fatigue, poor energy, increased sleepiness and low motivation affected their choices and ability to participate. Participants reported feeling left out and frustrated when they could not participate in an activity they were invited to, or aware of.

The data analysis revealed that PWPD reduced and modified their levels of physical activity due to a fear of having falls, or because they were actually experiencing falls. This change in behaviour also led to feelings of loss, as it changed both their participation, and that of their carer, in most areas of life. A large amount of research is happening in the field of falls prevention, and exercise as a treatment option for people who have fallen. PWPD have a higher rate of falls, suffer more injury from falls and have a longer length of stay in hospital following falls (PAUL; HARVEY; CANNING; BOUFOUS *et al.*, 2017). Mortality increases once poor balance and falls are impacting upon QOL (HELY; MORRIS; TRAFICANTE; REID *et al.*, 1999). Falls are also a determinant of poor QOL and lower life expectancy (FASANO; CANNING; HAUSDORFF; LORD *et al.*, 2017). The finding of this study, which analysed many exercise trials, suggests that exercise, as a treatment intervention, can be effective in reducing falls when delivered early in the disease process. Unfortunately it is often much later in the disease process when people are struggling with their mobility that treatment is sought.

A diagnosis of PD often leads to social withdrawal (O'BRIEN; CLEMSON; CANNING, 2016). Symptoms including a drawn face, sleepiness, tremor, dribbling from the mouth, fear of falling and soft voice were all reported by participants of this study as reasons why they often chose to stay home. For the carer of a PWPD in this study, this loss relates to a lost opportunity for themselves to connect within their own social needs. Both the PWPD and their carer reported this increasing social isolation as a loss and a feeling of disappointment. Many participants were aware of this upon their carer, which added further weight to their feeling of loss. Concern about how they may be perceived by others was also reported by participants and did influence their social outings either for social or exercise purposes.

“But we just don’t do anything now... So everything’s gone.”

(Carer for Participant C)

A person's ability to adapt to change and loss influences their choices and their participation.

"It's a change of life in every way, particularly when you've been active and mentally sharp as well because that goes. Your ability to even talk properly and noticing that, swallowing, little things like that, it's, it's an adjustment, you know. And I guess you can either be positive about that adjustment or let negativity come in about that adjustment. And, to be honest, I'm a mixture of both sometimes". (Participant S)

Hope for the future was an underlying theme for all participants. Hope for a status quo was a driving factor for participants, in their choices to continue to do their best to maintain current activity and levels of function. For those people who were participating in physical activity to help manage their symptoms, hope for a status quo was their driving force. Living their life at their current level with no further deterioration was a goal, and a change they could and have adapted to.

"I hope that there'll be no change. No further progression or anything like that". (Participant E)

The data from this study supports previous evidence that exercise programmes need to provide structure and hope as motivating influences regarding participation. When participants felt less stiff and more active after a session of physical activity, it fuelled their desire to continue to participate in physical activity, as they could feel that it made a difference.

Exercise information at time of diagnosis: None of the participants recalled being given any specific advice to exercise at the time of diagnosis. Achieving a diagnosis of PD is often a long and complicated process. For some, it is a relief to be able to put a label on their complex mix of symptoms. For others it is a shock, as they have never heard of PD before. Time to reach diagnosis and satisfaction with the explanation of the diagnosis has been shown to influence long term QOL (HAYES; FUNG; KIMBER; O'SULLIVAN, 2010). The data analysis revealed different time frames, and diverse explanations and expectations at the time diagnosis was communicated. There was a sense of uncertainty at the time of diagnosis for many:

"The doctor said to me one day, "I think you could well be suffering from Parkinson's" as a passing comment, you know" (Participant S)

The response of people interviewed in this study to receiving the diagnosis of PD was variable and included “I try to forget”, and “I minimised it”. All participants interviewed consistently reported a sense of resignation. Some then chose to stay resigned, taking direction as to their management only from their specialist, general practitioner, and family or friends. For these people, their health care professionals need to be specific with information regarding the benefit of physical activity, and continue to monitor and encourage participation as an important management strategy in their PD management.

Some participants took a more determined approach to their ongoing management after receiving their diagnosis of PD, and then actively started searching for choices they could make that would influence their health and well being outcome. The Internet and Google searches were common sources of further information, influencing their decisions being made. Provision of concise exercise and physical activity goals, and resources as to where to find recommended programmes would help these people direct their efforts effectively and more immediately.

“...then it was a matter of finding out what I could do, and combat it” (participant E)

The attitude of the diagnosing health professionals has an influence upon the attitude of the person being diagnosed. Participants reported feeling relieved when told that “it won’t kill you”, however they also reported not being able to recall all of the information that was exchanged at the time of diagnosis. What is discussed at time of diagnosis is important. Participants reported feeling overwhelmed, and the receptiveness of the PWP to the information exchange is variable. Those participants with a carer reported being grateful to have someone else there to help absorb the information. The relationship they have with their neurologist is only new, and early in the disease there is no established relationship with other health care professionals. The neurologist was reported by all participants as being the primary source of information at this early stage during diagnosis.

The data from this study suggests that people need a source of information around the time of diagnosis, more than just what the diagnosing doctor may provide. Health professionals who provide hope and practical means for management are essential. The messages PWP receive at this time need to be empowering and give people hope and a means of being able to help to manage and control their symptoms and expectations with what may lay ahead living with PD.

Perception of exercise: The terms physical activity and exercise were used in many different contexts throughout this study, which

complicated data analysis. Some people perceived the word ‘exercise’ as set formal classes in a gym type setting. The term physical activity was also used, however people seemed unfamiliar with its meaning, and did not consider ballroom dancing, riding a bike, tennis and walking as being versions of physical activity.

The comments, experience and attitudes of participants were quite dichotomous:

“I don’t want to exercise” (Participant M)

“Exercise always part of my life” (Participant E)

Those participants, who had always done some form of exercise, were doing their best to maintain some form of exercise. One participant consciously chose to engage in much more exercise:

“More active now than has ever been” (Participant N)

A very common thread for many participants was the perception that doing their activities of daily living was enough. Feedback, especially from medical professionals was often non-specific. Participants reported that when they were being told they are ‘doing well’ there was no indication that they could also be doing more. This interpretation reinforces the attitude of participants who honestly believed that the exercise and physical activity that they were doing is enough. Participants reported avoiding tasks that would lead to fatigue or that were perceived as difficult. This is in contrast to the evidence in the literature regarding the importance of high intensity of exercise (HIRSCH; FARLEY, 2009).

“I think just in living I’m getting enough exercise” (Participant F)

Some participants reported that they have never been specifically told to exercise, as a treatment modality for their PD. They have been quite compliant and taken advice from their medical practitioners, as directed.

“Do I need to do exercises? If there’s anything that can make me feel better or slow this down, I’ll do it”. (Participant T)

There is very strong evidence in the literature to support the concept of ‘exercise as medicine’. High intensity exercise has been shown to improve motor symptoms in humans with PD (ALBERTS; PHILLIPS; LOWE; FRANKEMOLLE *et al.*, 2016; FRAZZITTA; MAESTRI; BERTOTTI; RIBOLDAZZI *et al.*, 2015). It has also has been suggested that it may prove a neuroprotective effect (FRAZZITTA; MAESTRI; BERTOTTI; RIBOLDAZZI *et al.*, 2015; ZHOU; BARKOW; FREED, 2017).

Exercise programmes that challenge balance (CANNING; PAUL; NIEUWBOER, 2014) intensity (FISHER; WU; SALEM; SONG *et al.*, 2008; FRAZZITTA; MAESTRI; BERTOTTI; RIBOLDAZZI *et al.*, 2015) and amplitude (FARLEY; KOSHLAND, 2005) need to be delivered earlier in the course of disease progression than is commonly understood by the general population. There is very strong evidence in the literature that the Parkinson's brain has the capacity to reshape and respond to neuroplasticity in response to exercise (FARLEY; KOSHLAND, 2005; HIRSCH; FARLEY, 2009).

The data from this study revealed that few people were participating in exercise and physical activity at a level that may be considered therapeutic. There is a general misunderstanding that doing Activities of Daily Living (ADL) tasks is enough to alter disease progression. Specific information regarding effort and amplitude needs to be given, repeated, and reinforced in all interactions between health professionals and PWP, to avoid the misinterpretation that many have about what constitutes everyday physical activity and the physical activity associated with disease management.

Information and education:

The information people had to draw from was very inconsistent across all the participants interviewed. The Internet was the most common source, but most people reported a very ad hoc manner in which information had been gathered over the years.

The researcher made an assumption that all participants in the study were literate. One participant was not, and possibly a second one also had reading difficulty. Nearly all of the information available to people is in written form. A number of participants reported a strong preference to face to face sharing of and learning of new information. Some reported their only source of information was from their own experience of seeing other people who had PD.

“...and he had Parkinson's really bad. Really bad... He had it really bad. And he hunched right over, and he ... That's a big fear of ending up that way”. (Participant T)

In relation to physical activity, all of the participants understood the general principles of exercise and physical activity and that they should “use it or lose it”. Very few actually knew or understood the specific deficits associated with movement and PD, and did not know that exercise for PD needs to be specific, large amplitude and intense to lead to the positive physiological changes participants are looking for (CANNING; PAUL; NIEUWBOER, 2014; FARLEY; KOSHLAND, 2005; FRAZZITTA; MAESTRI; BERTOTTI; RIBOLDAZZI *et al.*, 2015).

Some participants had concurrent health conditions, in particular, heart disease. They have received mixed messages from health professionals and struggled to know what is best to do without specific

and directed instructions. The only exercise classes available to PWPD in the geographic areas of the study were classes targeted for people with chronic cardiorespiratory illnesses or falls prevention. These particular programmes do not address the specific need for amplitude, and tend to shy away from intensity as it is directed towards a population of people who have had some form of cardiac or respiratory compromise. The power of groups and the benefit of face to face clinical contact for PWPD should not be overlooked. Many participants did not attend support groups, however exercise groups could be a source of support and information exchange.

One participant's carer reported that the researcher was the first person, other than the neurologist, in 17 years to sit down and talk about PD with them. They were quite unaware of non-pharmacological treatment options and services available in the wider health industry, despite being active, working members of their community.

Other participant's revealed that the researcher was the "first person" they have ever talked to about behaviours they could not understand. One participant was relieved that he wasn't "going mad" as he was unaware that visual hallucination could be part of PD. Another participant did not realise that his erratic night time behaviour could also be attributed to his PD.

"I don't think I've ever told anybody that before. They'd probably think I was bloody mad". (Participant U).

The data collected revealed that many people living with PD in WNSLHD poorly understood the full range of symptoms across the length of the disease span and were unaware of non pharmacological management options. Education and information exchange regarding motor and the non-motor symptoms of PD need to be further explored and addressed. When PWPD gather at an exercise group, a support group, or a social occasion, these are all opportunities for information exchange.

Psychological support: Many people are aware of the physical manifestations of PD. What is less talked about, and people are generally not prepared for, is the psychological aspect of diagnosis and then the ongoing concerns of living with PD. Those participants whom had received some level of psychological support, including Cognitive Behavioural Therapy were very appreciative and welcoming of this. Those who had not received this had not considered it as a management option.

Psychological support may play a larger role in participation in physical activity when it can help support a positive and pro-active attitude towards health management.

"I think most, most people should tap into it because the, the mind will, I think, dictate a lot of your, your direction and, if, if

your attitude can be adjusted or, or steered in the correct direction of how, what sort of attitude you should have to this, this situation, it can certainly make it a lot more manageable and a lot more beneficial I think for your outcome.” (Participant S)

A feeling of anxiety was apparent for all participants. Every person interviewed described feelings of fear of the future, and anxiety related to uncertain future. This anxiety has an impact on their everyday functioning, planning for the future, social interactions and participation in physical activities. Anxiety is interconnected into grief and loss, and is a factor forming attitudes towards physical activity.

“My greatest fear is losing my independence” (Participant E)

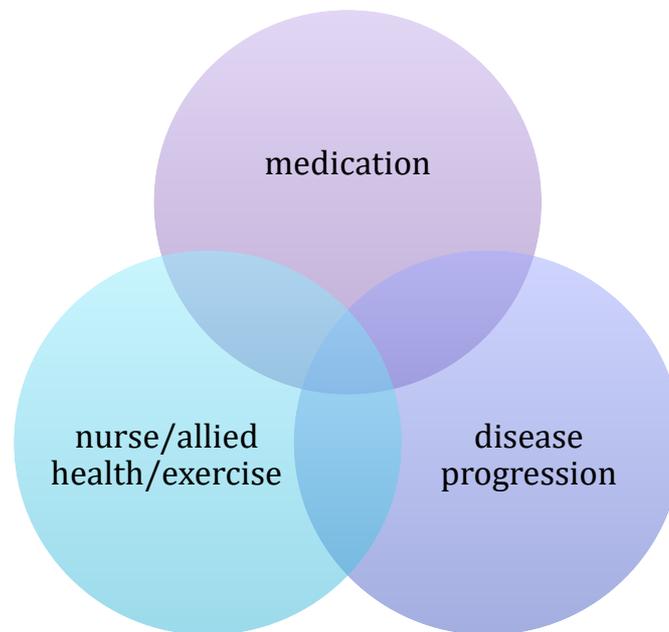
Participants reported feeling of a “fear” for the future, and the “dreadfulness” of being uncertain about what was ahead. These powerful words such as “dread”, “fear” and “inadequate” were used often and every participant was conscious of the uncertainty that lay ahead. Managing on a daily basis was reported to be difficult and unpredictable as symptoms can vary from day to day. Participants reported that they do not like to plan and make commitments due to an uncertainty as to their own well being on any given day. This had an effect on social outings and participation in activities of daily living. A concern regarding uncertainty on the larger scale relating to independence, posture, ability to do functional tasks, memory, drooling, voice and facial expression were all common experiences. This uncertainty stemmed from their own lived experience, from their own experience of seeing friends or relatives with PD, and from a reported lack of education and information about PD.

Psychological support is not often considered as routine care for a PWPD. The data collected in this study revealed that having some form of psychological input, and positive empowering information and messages about treatment options leads to improved participation with exercise programmes.

The informative, physical and psychosocial needs for a PWPD changes with time. It cannot be expected that all the information someone may require can be given at the time of diagnosis. Information needs to be exchanged at a time when the person is receptive to it. This may be at multiple times along the timeline for someone living with PD.

CONCLUSION

A traditional approach to management for a PWPd is multifactorial, and primarily involves medical management by a person's neurologist or GP with medication. As the disease progresses other health professionals may become involved including Speech Pathologists, Physiotherapists, Occupational Therapists and Nurses.

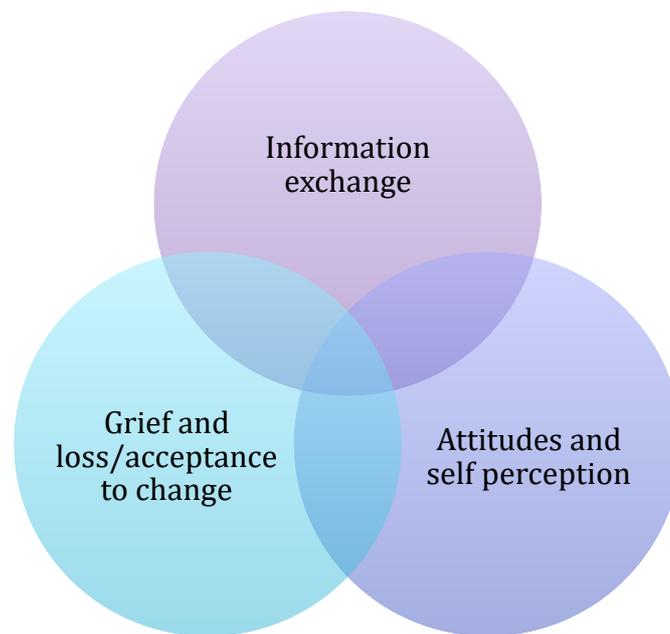


The data analysis from this study suggests that a person's attitude and emotional response towards physical changes, managing loss, and understanding of the role of exercise within the complex nature of their PD influences participation in physical activity. Attitude is itself a multifactorial process, and one, which develops lifelong. Those participants who actively sought resources to influence their attitude and behaviour were more likely to participate in physical activity.

In rural areas exercise and physical activity is often associated with work, and not associated as an activity chosen for improved health outcomes. When developing health programmes for PWPd, exercise being presented within a functional context may be more appropriate, especially for men. The importance for physical activity focused on intensity and amplitude in being able to modify disease progression and allow for improved QOL years needs to be communicated with PWPd at all stages of their disease. The power of groups should also not be underestimated. Many people choose not to participate in PD support groups, however will attend and share information in an exercise group context.

At a time when the number of people with PD is growing due to an aging population, it is timely that best QOL outcomes for PWPd continue to be at the forefront for health services. A traditional health service that is reactive to injury and illness may need to redirect resources towards wellbeing and education for people at an earlier stage of their illness, a

stage when behaviour change, attitude, and neuroplasticity can all be optimised. The data collected in this study supports the need to recognise the themes of self-perception, grief and loss and information exchange as the basis for health service delivery. Delivering information without support is not enough. Services that incorporate education with physical activity, and psychological support will best meet the needs of PWPd. The various dimensions of access which include accessibility, availability, acceptability, affordability, adequacy and awareness (SAURMAN, 2016) all need to be considered in conjunction with this data when informing service planning and delivery of services for PWPd.



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APPENDIX (a) Interview questions

“What factors influence engagement with physical activities of persons living with Parkinson’s Disease in Western NSW”

Interview questions:

Thank-you for agreeing to participate in this research project. The aim of today’s interview is to talk about your level of physical activity and the support services you currently access. I would also like to explore services you would like to access in the future.

The interview will take approximately 1 hour and will be audio-recorded. After the interview, the recording is transcribed and any information that would identify you will be removed to protect your privacy. The recording can be stopped at any time at your request. If

you find that you need a break for a little while, just let me know and we can take some time out and then commence the interview again.

Demographic Details:

Age	
Gender	
Time since diagnosis	
Support from family	
Support from formal carer	
Services received at home	
Level of mobility (walking with/without assistance)	
Driving capability	

Questions:

Please describe how long ago you were diagnosed with PD. (Whom was it diagnosed by? Did you need to travel far for tests or the diagnosis?)

Can you tell me what was it like when you received the diagnosis? Please explain.

Can you describe for me your physical activity levels throughout the different stages of your life?

Have you experienced a decline in your participation in everyday and other physical activities leading up to your diagnosis? And now? Why do you think this is so?

Do you know of any exercise or physical activity programmes available in (Cowra/Forbes/Parkes)? Do you participate in any of these? Do you like to exercise? (Why/why not?)

What is it like to live with PD? What are the main problems/issues you have? Do you experience frustrations and hurdles, and if so, what are they?

What costs or financial impacts do you experience with having PD?
Does this affect your participation in physical activities? Please explain.

Where do you prioritise physical activity in the treatment and management of your PD on a scale of 1-10?

What information or help have you received that you have found most beneficial? Are there other services you wish you had access to? Why?

Are you actively pursuing any type of other therapies?

What do you hope your future will look like in 12 months...5 years...10 years from now?

APPENDIX (b) Invitational flyer

DO YOU, OR SOMEONE YOU KNOW
HAVE

PARKINSON'S DISEASE



OPPORTUNITY TO PARTICIPATE IN RESEARCH:

- Must have a diagnosis of Parkinson's Disease.
- Be willing to participate in a confidential interview in your own home, or a place you choose.
- Be living in the Central West, at least an hour away from Dubbo, Orange and Bathurst.
- Are willing to talk about how Parkinson's Disease impacts upon aspects of your lifestyle, including physical activity.

If you would like to participate, or want further information, please call Jennifer Mannell on 63328972 or 0403403839 and an information pack can be sent to you.