

Prevalence and Physiotherapist Awareness of Shoulder Pain and/or Stiffness as an Early Symptom of Parkinson's Disease: An Australian Perspective

Sarah Walmsley *PhD*

Lecturer, Discipline of Physiotherapy, School of Health Sciences, Faculty of Health and Medicine, The University of Newcastle, Callaghan, Newcastle, Australia

Darrell Chandley-Pascoe *BPhy (Hons)*

Discipline of Physiotherapy, School of Health Sciences, Faculty of Health and Medicine, The University of Newcastle, Newcastle, Australia

Evelyn Collins *BNursing*

Parkinson's disease clinical nurse consultant, John Hunter Hospital, New Lambton Heights, Newcastle, Australia

Jodie Marquez *PhD*

Senior lecturer, Discipline of Physiotherapy, School of Health Sciences, Faculty of Health and Medicine, The University of Newcastle, Callaghan, Newcastle, Australia

ABSTRACT

Musculoskeletal pain is known to be an associated symptom of Parkinson's disease (PD). However, there is limited literature that describes the likelihood of shoulder pain and/or stiffness as an early presentation of the disease. The aim of this study was to determine the prevalence of shoulder pain and/or stiffness as an initial symptom of PD and to gain an understanding of physiotherapy awareness of this early symptom. Two cross-sectional, purpose-designed surveys were undertaken. A postal survey was mailed to 189 patients with PD and an online survey was emailed to 336 physiotherapists. A response rate of 63% was obtained for PD patients and 23% for physiotherapists. Of the patients with PD, 13% reported onset of shoulder pain and/or stiffness within 5 years prior to diagnosis, with no reported past history of shoulder issues. Of these patients, 8% specifically reported shoulder symptoms as the initial manifestation of the disease. However, 74% of physiotherapists surveyed were unaware of the potential for the early presentation of this symptom. This study has reinforced the potential for shoulder pain and/or stiffness to be an early symptom of PD and has identified a key area for knowledge improvement for physiotherapists in order to reduce the potential of misdiagnosis and mismanagement of this symptom.

Walmsley, S., Chandley-Pascoe, D., Collins, E. & Marquez, J. (2020). Prevalence and physiotherapist awareness of shoulder pain and/or stiffness as an early symptom of Parkinson's disease: An Australian perspective. *New Zealand Journal of Physiotherapy*, 48(3), 138–147. <https://doi.org/10.15619/NZJP/48.3.05>

Key Words: Parkinson's Disease, Shoulder Pain, Shoulder Stiffness, Physiotherapy, Diagnosis

INTRODUCTION

Parkinson's disease (PD) is the second most common neurodegenerative disorder in Australia (Deloitte Access Economics, 2015). The exact prevalence of PD is difficult to determine; however, it is estimated that there are 294 per 100,000 people with the disease living in Australia (Deloitte Access Economics, 2015) and 210 per 100,000 people in New Zealand (Myall et al., 2017). This number is expected to increase with the growing population, and it has been suggested that it may double within the next 15 years (Hirsch et al., 2018). PD is a chronic, progressive condition associated with lifelong disability (Bohingamu Mudiyansele et al., 2017; Haddad et al., 2017). This places a considerable burden on individuals, family, the health system, and society in general (Bohingamu Mudiyansele et al., 2017). The financial burden alone for an individual living with PD in Australia has been suggested to be approximately \$32,500 per year (Bohingamu Mudiyansele et al., 2017). Symptoms of the disease are due to the progressive

loss of dopamine producing neurons in the basal ganglia, and people living with Parkinson's disease (PLWPD) generally do not present with symptoms until 60-80% of dopamine loss has occurred (Ya-Ting et al., 2015). Characteristic symptoms include tremor, muscle rigidity or stiffness, bradykinesia, and postural instability. More specifically, shoulder pain and/or stiffness has been reported as one of a number of early clinical manifestations of the disease and may be present years prior to the onset of the more commonly recognised features (Cleaves & Findley, 1989; Riley et al., 1989; Stamey et al., 2008; Schrag et al., 2014, Ya-Ting et al., 2015).

Shoulder pain has been reported to be more prevalent within PLWPD populations compared to the general population (Defazio et al., 2008; Madden & Hall, 2010). The underlying reason for the early presence of shoulder symptoms in PD has not been ascertained. It has, however, been speculated that rigidity and bradykinesia may go undetected due to being generalised and not specifically related to function. These

motor symptoms may lead to immobility, which may precipitate shoulder pain and dysfunction (Stamey et al., 2008). Shoulder pain and/or stiffness as an initial manifestation of PD is often unrecognised, misdiagnosed or improperly treated (Stamey et al., 2008). Misdiagnoses include arthritis, bursitis, rotator cuff disease and frozen shoulder (Jankovic, 2008; Riley et al., 1989; Stamey et al., 2008). In a survey of the Canadian population to investigate the relationship between PD and essential tremor, it was reported that 19% of 150 PLWPD described a diagnosis of frozen shoulder, or a spontaneous onset of pain and restriction of the shoulder (Riley et al., 1989). A similar English study reported 12% of 100 PLWPD described shoulder pain as their initial PD symptom, including 8% diagnosed with frozen shoulder prior to a diagnosis of PD (Cleeves & Findley, 1989). An American study also reported 11% of 309 PLWPD complained of shoulder pain, with 20% reporting their shoulder pain preceded the onset of motor symptoms (Stamey et al., 2008). Furthermore, Madden and Hall (2010) compared PD to controls, and concluded PLWPD have six times the odds (Odds ratio [OR] = 6; 95% confidence interval [CI] = 1.69–21.6; $p = 0.006$) of having shoulder pain compared to those without PD. Failure to recognise this pain as a presenting symptom of PD could delay correct diagnosis as well as lead to unnecessary and potentially costly procedures (Stamey et al., 2008).

Early diagnosis and treatment of PD is important to limit the impact of the disease on quality of life and, potentially, lower long-term treatment costs (Deloitte Access Economics, 2015; Pagan, 2012). Schrag et al. (2014) found the rate of progression is faster in early PD compared to later in the disease course. As the condition progresses, the severity of symptoms increase and the burden on quality of life, as well as the proportion of costs involved, become greater (Deloitte Access Economics, 2015). Despite no cure being currently available for PD, regular exercise has been found to have a positive role, reduce the symptom burden, and slow the decline in functional ability, especially early in the disease (Bridgewater & Sharpe, 1996; Flynn et al., 2019). Cardiorespiratory fitness has also been shown to be correlated with greater functional activity and ability, and as such, improved endurance could lead to improvements in overall function (Schenkman et al., 2012). The benefit of initiating medication early within the disease progression remains unclear (Connolly & Lang, 2014). However, evidence suggests the use of monoamine oxidase type B inhibitor in early PD provides small symptomatic benefit, and earlier initiation of rasagiline has been associated with slower long-term progression of symptoms (Hauser et al., 2009; Ives et al., 2004). Therefore, recognition of any early symptom of PD, including shoulder pain and/or stiffness, may facilitate earlier treatment and provide the best opportunity to maximise patient outcomes.

Persons experiencing a painful and/or stiff shoulder will frequently present for physiotherapy treatment. During 2015–2016, physiotherapists were the most common referral from GPs within Australia (Britt et al., 2016), with the majority of referrals being made for musculoskeletal problems (Dennis et al., 2018). Furthermore, over half of the people who access physiotherapy are self-referred (Dennis et al., 2018). Arguably, therefore, it is important that physiotherapists, along with other health professionals, recognise the potential for shoulder pain and/or stiffness to be an early manifestation of PD so

that appropriate management can be initiated. Therefore, the research questions posed for this study were:

1. What is the prevalence of shoulder pain and/or stiffness as an early symptom reported by newly diagnosed PLWPD in an Australian population?
2. What are the characteristics and typical management strategies sought and received by PLWPD for shoulder pain and/or stiffness?
3. How aware are physiotherapists of shoulder pain and/or stiffness as a symptom of PD, and what are the typical interventions they apply?
4. Are there any sub-groups of physiotherapists more aware of shoulder pain and/or stiffness as a symptom of PD?

METHODS

Two cross-sectional surveys were conducted. The first involved a postal survey of PLWPD to answer questions 1 and 2. The second involved an online survey of practising physiotherapists to answer questions 3 and 4. As there is no validated tool available that addresses the research questions, each survey was designed by the research team specifically for the purposes of this study. Both surveys were piloted with members of the respective target populations and revised prior to final dissemination. Involvement in this study by both PD and physiotherapy participants was voluntary, and no compensation was provided. Consent was implied if the anonymous postal survey was returned or the anonymous online survey was submitted.

Participants

Recruitment of PLWPD

Potential PLWPD participants were all newly diagnosed patients who attended the Parkinson's clinic at a regional hospital in New South Wales between January 2014 and December 2018 (5-year period). The time since presentation to the clinic was restricted to the past 5 years to limit the risk of recall bias for participants when attempting to report initial symptoms and treatments. Cognitive decline is a continuous process that affects nearly all PLWPD over time and may lead to dementia in advanced disease (Aarsland et al., 2017). We did not exclude those with advanced disease or dementia (Balash et al., 2017), and consequently, we may have recruited those who have reduced capacity to evaluate and self-report their symptoms.

Recruitment of physiotherapists

Potential physiotherapist participants were all registered physiotherapists located within the local health district (LHD) who were either working in private clinics or outpatient physiotherapy departments at private and public hospitals. Employment type was restricted to private clinics and hospital outpatient departments to ensure the target was physiotherapists who would likely be responsible for the management of patients presenting with shoulder pain and/or stiffness as an initial symptom. Private clinics within the LHD were identified using the "find a physio" function on the publicly available Australian Physiotherapy Association website. The private and public hospitals within the LHD were identified on the New South Wales government website.

Design

The questionnaire targeting PLWPD was a postal mail survey (Appendix A). The instrument consisted of 18 questions, incorporating both closed- and open-ended questions. It was categorised into three sections: section 1 requested demographic information; section 2 requested information regarding the onset of PD and initial symptoms; and section 3 sought further information if the patient had experienced shoulder symptoms, and if so, the type of treatment they received from either a physiotherapist or other health professional. A letter of invitation and the survey were mailed to the potential participants' last known postal address. Potential participants were asked to complete the anonymous survey and return it to the researchers in a reply post-paid envelope.

The questionnaire for physiotherapists was an online survey (Appendix B). It consisted of 17 questions and, similarly, incorporated closed and open-ended questions divided into three sections. Section 1 requested demographic and work experience information about the therapist, section 2 asked questions regarding typical physiotherapy management of shoulder pain and/or stiffness, and section 3 enquired about their knowledge of pain and/or stiffness as an early presenting manifestation of PD and management of this condition. Each practice/hospital was contacted by telephone to determine the number of potential participants at each site and to identify a contact email address. Each practice/hospital was sent an email and a letter by post to the address given. The email contained a flyer describing the project as well as a link to an information statement and the survey. Similarly, flyers corresponding to the number of physiotherapists working at the location were sent with the postal letter. The online survey was completed using QualtricsSM software, a secure platform provided by the research institution. Two reminder emails were sent to each physiotherapy setting at two and four weeks after the initial distribution.

This study was approved by the Hunter New England Research and Ethics Committee (H-2019-0028) and co-registered with the University of Newcastle Human Research Ethics Administration (2018/ETH00631). Informed consent was obtained from both PLWPD and physiotherapists.

Data analysis

Descriptive statistics, including means and standard deviations (SD), were calculated for demographic and ordinal data. A Pearson product-moment correlation coefficient was computed to assess the relationship between continuous variables. When variables were measured on an ordinal scale, a Spearman's correlation was used. Chi-square tests were used to assess the relationship between two categorical variables, while Fisher's exact test was used when cells had a frequency of fewer than five subjects. Regression analysis was conducted to assess the relationship between knowledge of shoulder pain/stiffness in PD and other variables. Statistical significance was set at $p < 0.05$. STATA 14.2 statistical software (STATA Corp, Texas) was used for all analysis. Data from open-ended questions were collated verbatim and then coded independently by two examiners. The open coding method of grounded theory, with line by line examination of responses and the development of a coding tree

that represented the discrete ideas underlying each sentence or word, was used (Corbin & Strauss, 2008). This includes data describing the initial PD symptom, history of shoulder problems, treatment received by PLWPD, treatment prescribed by physiotherapists, and factors that would indicate PD.

RESULTS

Participants with Parkinson's disease

A total of 189 PLWPD were invited to participate in the study; of these 120 returned completed surveys (63%). The demographic characteristics of the respondents are presented in Table 1.

Table 1

Demographic Characteristics of Participants with Parkinson's Disease

| Demographic | n (%) ^a |
|--------------------------------------|--------------------|
| Age (years) | Mean 68.4, SD 9.5 |
| Age at PD diagnosis (years) | Mean 59.7, SD 9.7 |
| Gender | |
| Male | 62 (52) |
| Female | 58 (48) |
| Private health insurance | 84 (70) |
| Born in Australia | 100 (83) |
| Aboriginal or Torres Strait Islander | 0 (0) |
| Highest level of education | |
| Did not complete high school | 15 (13) |
| School certificate (year 10) | 32 (27) |
| HSC (year 12) | 6 (5) |
| Certificate/diploma | 34 (28) |
| Bachelor's degree | 22 (18) |
| Postgraduate degree | 9 (8) |

Note. PD = Parkinson's disease; SD = standard deviation.

^a Except where indicated.

Description of initial symptoms

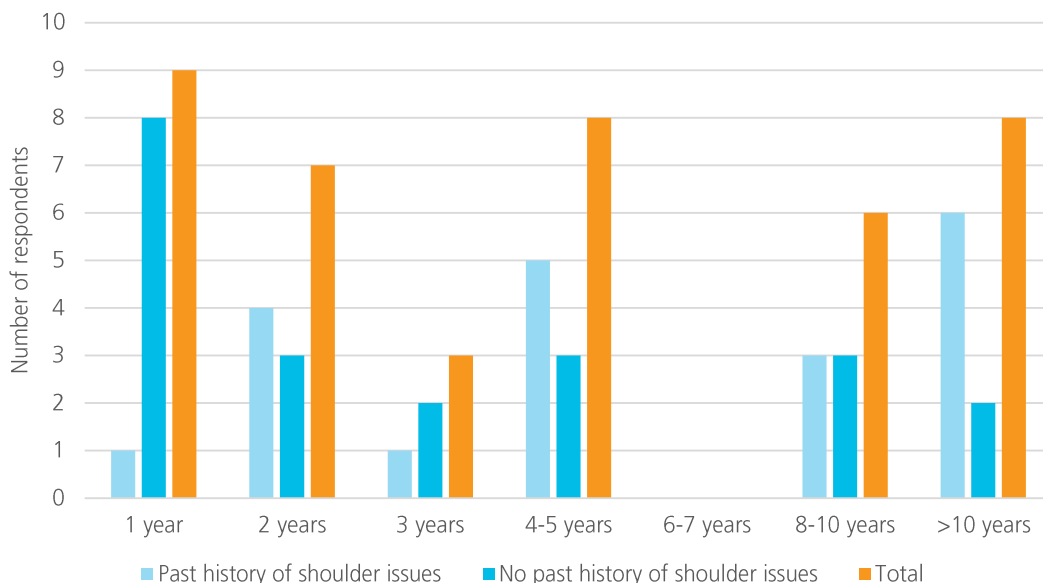
Tremor or shaking was reported as the initial recognised symptom by 57% of participants. The tremor occurred most predominantly in the upper limb: right (16%), left (12%), and unspecified (8%). Other reported initial symptoms included pain and stiffness (16%), difficulty with writing and hand function (13%), disturbed balance and gait (11%), reduced arm movement (9%), loss of smell (8%), weakness (5%), slow movement/bradykinesia (5%), altered speech (3%), paraesthesia/numbness (2%), and vivid dreams (1%).

Participants with shoulder pain and/or stiffness

The majority of participants (73%) reported having experienced shoulder pain and/or stiffness. Of those, 53% reported the onset of shoulder symptoms prior to being diagnosed with PD, whilst 20% were "unsure" and the remainder (26%) reported the symptoms occurred after diagnosis. Of those reporting shoulder pain and/or stiffness prior to diagnosis, 43% reported "no past history of shoulder problems or injuries". Of these, 80% reported the symptoms manifested within 5 years before diagnosis, including 55% who reported the symptoms occurred

Figure 1

Onset of Shoulder Pain and/or Stiffness Prior to a Diagnosis of Parkinson's Disease



within 24 months prior to diagnosis, as shown in Figure 1. Specifically, 8% of participants reported shoulder symptoms as their initial manifestation of the disease, which was categorised as either stiffness (3%), pain (3%) or “shoulder problems” (2%).

Of the participants who reported shoulder pain and/or stiffness prior to diagnosis and a past history of shoulder issues, rotator cuff injury (42%) was the most reported issue. Other previous shoulder problems included arthritis (19%), frozen shoulder (19%), injury from long-term work/sport (12%), bursitis (8%), fracture or bone spur (8%), and shoulder dislocation (4%). There was no statistically significant association between shoulder pain and/or stiffness as an initial symptom, with any other variables including age ($r = -0.13, p = 0.27$), age at PD diagnosis ($r = 0.07, p = 0.59$), gender ($\chi^2 = 0.42, p = 0.52$) or education level ($p = 0.48$).

Participants who received physiotherapy

Of the participants who had experienced shoulder pain and/or stiffness, 56% had received physiotherapy. The percentage of participants accessing physiotherapy did not differ significantly whether the shoulder symptoms occurred before or after diagnosis. A description of physiotherapy treatment/management is presented in Table 2. Of the participants who received physiotherapy, 16% reported that the physiotherapist referred them to other services to review the shoulder symptoms. This included 8% to an orthopaedic surgeon, 4% to a doctor/GP, and 2% to a chiropractor or another physiotherapist.

Of the participants with shoulder pain and/or stiffness, 48% had received treatment other than physiotherapy. This included cortisone injection (20%), acupuncture (8%), surgery (5%), massage (5%), exercises (4%), medication (3%), and alternative therapy (2%).

Table 2

Physiotherapy Treatment for Shoulder Symptoms as Reported by Participants with Parkinson's Disease

| Intervention | n (%) |
|--------------------------|---------|
| Stretching exercises | 35 (71) |
| Home exercises | 34 (69) |
| Strengthening exercises | 31 (63) |
| Massage | 25 (51) |
| Education and advice | 19 (39) |
| Heat | 18 (37) |
| Dry needling/acupuncture | 11 (22) |
| Taping | 7 (14) |
| Ice | 7 (14) |
| Vibration | 1 (2) |

Physiotherapists

A total of 157 health facilities were identified for inclusion in the study, consisting of 118 private practices, 27 public hospitals, and 12 private hospitals. However, at seven private practices and six public hospitals, the physiotherapist was unable to be contacted. A total of 144 facilities were therefore invited to participate in the study; two private practices declined participation, and 10 private hospitals were excluded because they did not provide outpatient physiotherapy. A total of 336 physiotherapists were identified, with 76 (23%) responding to the survey, as shown in Figure 2. The demographic characteristics of the physiotherapy participants are described in Table 3.

Figure 2

Flow of Physiotherapy Participants Through the Study

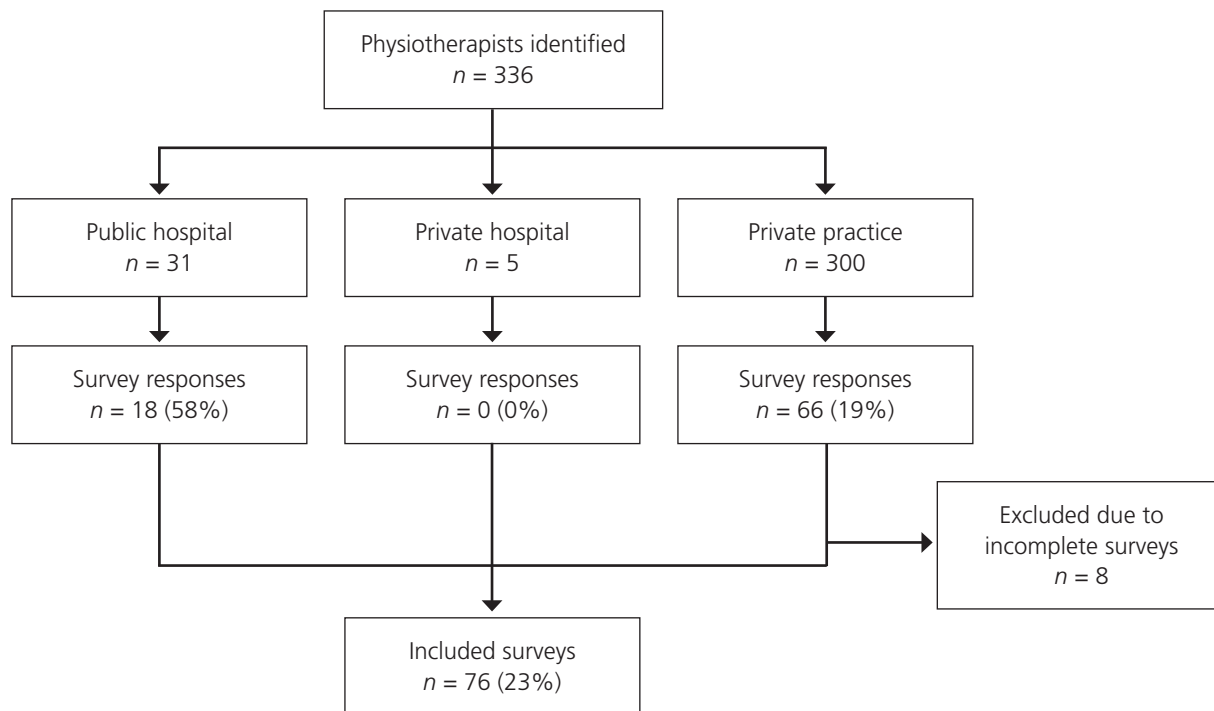


Table 3

Demographic Characteristics of the Physiotherapist Participants

| Demographic | n (%) |
|--|---------|
| Gender | |
| Male | 18 (24) |
| Female | 58 (76) |
| Highest physiotherapy qualification | |
| Graduate diploma | 8 (11) |
| Bachelor's degree | 51 (67) |
| Master's degree | 17 (22) |
| Doctorate | 0 (0) |
| APA titled | 18 (24) |
| Sports | 6 (33) |
| Musculoskeletal | 5 (28) |
| Sports and exercise | 2 (11) |
| Neurology | 1 (6) |
| Musculoskeletal and sports exercise | 1 (6) |
| Not specified | 3 (17) |
| Fellow of Australian College of Physiotherapists | 2 (3) |
| Years practising physiotherapy | |
| 0 to 2 | 10 (13) |
| 3-5 | 10 (13) |
| 6-10 | 15 (20) |
| 11-20 | 9 (12) |
| 21-30 | 12 (16) |
| Over 30 | 20 (26) |

Note. APA = Australian Physiotherapy Association.

Treatment of shoulder pain and/or stiffness

Of the 76 respondents, 95% (n = 72) reported treating patients with shoulder pain and/or stiffness. The average number of patients per month varied from 0 (1%), 1–5 (47%), 6–10 (38%), 11–15 (13%) to >15 (1%). The reported typical management for shoulder pain and/or stiffness and the action taken if the patient did not respond to normal management is presented in Table 4.

Shoulder pain and/or stiffness as an early symptom of Parkinson's disease

The majority of respondents (74%) reported that they were unaware that shoulder pain and/or stiffness could present as an early symptom of PD. There was no statistically significant association between awareness of the early symptom and level of qualification (p = 0.19), being titled (Chi² = 1.15, p = 0.28), work setting (Chi² = 0.94, p = 0.33), number of years working (p = 0.75) or gender (Chi² = 0.75, p = 0.78). Of the 26% (n = 20) that did recognise this early symptom of PD, the presence of tremor was the most reported factor of patient presentation that raised suspicion of PD (60%). Other reported factors included gait impairments or reduced arm swing (45%), masked facial expression (30%), rigidity (30%), stiffness (25%), changes to speech (20%), reduced coordination/proprioception (20%), posture (20%), and balance issues or recent falls (15%). Of these 20 respondents, 85% further indicated that the management approach of shoulder pain and/or stiffness would change if PD was suspected. Altered management included referring the patient to their GP (80%); completing a more detailed assessment, including neurological assessment (65%); and referring the patient to a neurological physiotherapist, neurological support service or exercise group (50%).

Table 4*Physiotherapy Management of Shoulder Pain and/or Stiffness*

| Management | n (%) |
|--|----------|
| Typical management | |
| Education and advice | 68 (89) |
| Strengthening exercises | 68 (89) |
| Stretching exercises | 56 (74) |
| Manual therapy | 53 (70) |
| Referral to GP for further management, e.g. corticosteroid injection | 17 (22) |
| Dry needling | 13 (17) |
| Referral for orthopaedic opinion | 12 (16) |
| Electrophysical agents | 7 (9) |
| Taping | 5 (7) |
| Hydrotherapy | 2 (3) |
| Management if the patient doesn't respond to normal management | |
| Refer back to GP or medical officer in a hospital setting | 62 (82%) |
| Manage with another physiotherapy option | 27 (36%) |
| Discharge with exercises and advice | 8 (11%) |
| Refer to another health professional | 7 (9%) |
| Refer to specialist | 5 (7%) |
| Imaging | 4 (5%) |
| Continue to work the patient | 2 (3%) |

DISCUSSION

The aim of this study was to investigate the prevalence of shoulder pain and/or stiffness as an early symptom of PD within an Australian population, and to gain an understanding of the physiotherapist awareness of this early symptom. This study used surveys of both persons diagnosed with PD as well as physiotherapists to explore these issues. To our knowledge, this is the first study of its kind to gather information from these two sources, which may facilitate earlier recognition and subsequent management of this disorder.

It is well documented that musculoskeletal pain is associated with PD (Broen et al., 2012; Ha & Jankovic, 2012; Valkovic et al., 2015). However, there is limited evidence reporting its presence as an initial PD symptom. Nevertheless, pain and stiffness related to the shoulder have been reported as an early symptom of the disease by a number of authors (Cleeves & Findley, 1989; Madden & Hall, 2010; Riley et al., 1989; Stamey et al., 2008; Schrag et al., 2014). In the current study, approximately three-quarters (73%) of PLWPD reported having experienced shoulder pain and/or stiffness in the past or currently. This is higher than the reported 38% for a general Australian population aged 55-74 years (Hill et al., 2010). Our findings are consistent with a study of 25 American PLWPD (Madden & Hall, 2010), but the prevalence is also higher than in another two studies that reported between 11 and 43% (Riley et al., 1989;

Stamey et al., 2008). This may be explained by differences in research methods, whereby Stamey et al. (2008) performed a retrospective analysis in which shoulder pain was not specifically sought during the examination, potentially resulting in under-reporting. Similarly, we found the peak onset of shoulder symptoms to be 0–24 months prior to diagnosis, which is consistent with earlier reports (Riley et al., 1989), as was the 8% incidence of shoulder pain, stiffness or “shoulder problems” as the initial symptom (Cleeves & Findley, 1989; Riley et al., 1989). Furthermore, although not assessed in our study, two other studies have reported other typical symptoms of the disease present on the ipsilateral side to the shoulder symptoms in 16 out of 19 cases (Riley et al., 1989) and all 12 cases (Cleeves & Findley, 1989).

The pathophysiological process related to the development of shoulder symptoms in PLWPD has not been determined. It is postulated that rigidity and bradykinesia could lead to immobility and predispose subsequent shoulder dysfunction and discomfort (Stamey et al., 2008). As the aetiology is unclear, the misdiagnosis of PD-related shoulder symptoms may commonly occur. This may have occurred in those respondents reporting the onset of pain and/or stiffness prior to PD diagnosis and a past history of shoulder problems. Of this sample, 25% reported the onset of symptoms within 24 months of a PD diagnosis, and had received a diagnosis of either frozen shoulder, rotator cuff tear, bursitis or arthritis – all of which have been identified as potential misdiagnosis for PD-related problems (Jankovic, 2008; Riley et al., 1989; Stamey et al., 2008). Findings from previous research are similar: one study found 8% of PLWPD reported frozen shoulder as their initial PD symptom (Riley et al., 1989). Another study reported that 8% of PLWPD sought medical advice for their shoulder pain prior to diagnosis of PD and received a diagnosis of frozen shoulder (Cleeves & Findley, 1989). Therefore, it is possible that recognition of this symptom as part of the PD disease process could have resulted in earlier and potentially more appropriate treatment for this group of PLWPD.

With the evidence supporting shoulder pain and/or stiffness as an early symptom of PD, it is essential that health professionals both recognise and understand how to appropriately manage a patient with this presentation. Our results demonstrate limited knowledge of shoulder symptoms as an initial symptom of PD, with only 26% of respondents reporting awareness of this relationship. This lack of awareness may result in patients receiving inappropriate investigations and treatment, resulting in delayed management of the disease. To our knowledge, this has not previously been investigated, and comparison with other cohorts of physiotherapists is not possible. Our responses included physiotherapists from metropolitan, rural, and remote areas, with a large distribution in years of experience and average number of patients treated with shoulder pain and/or stiffness each month. Therefore, this study provides a good approximation of the overall Australian physiotherapy population and suggests that the lack of awareness is across multiple physiotherapy domains.

The physiotherapy treatment for shoulder pain and/or stiffness reported by the physiotherapists was very similar to that reported by the PLWPD. The main variation was 89% of

physiotherapists reported providing education and advice, while only 39% of patients reported receiving it. The signs and symptoms that the physiotherapists reported that raised suspicion of PD included tremor; gait impairments; impaired writing and hand function; slow or altered speech; altered or reduced sense of smell; and reduced balance, proprioception, and coordination. All of these were common initial symptoms reported by PLWPD participants within our study as well as by other research (Sveinbjornsdottir, 2016). Furthermore, the majority (82%) of physiotherapists reported they would refer the patient to a GP or medical officer if their symptoms did not respond to normal management, which could lead to further delays in receiving appropriate management. However, it highlights the importance for all medical professionals to recognise shoulder pain and/or stiffness as a potential early symptom of PD, and the appropriate treatment path to follow.

There are a number of limitations to this study. Both surveys had good response rates from the target populations (Daikeler et al., 2020). However, there may be limitations with external generalisability, as the PLWPD were sourced from one clinic and a limited number of physiotherapists sourced from one LHD. Furthermore, both surveys were subject to responder bias and may have attracted patients with shoulder pain and physiotherapists with an interest in PD. Although typical treatments provided/received for shoulder pain/stiffness were recorded, the response to treatment was not investigated within the study. Also, the surveys used were designed for this study, and although they were piloted, they are not validated instruments. As a result, the use of a non-validated instrument with a focus on pain/stiffness may have led to an overestimation of self-reported shoulder symptoms (Buhman et al., 2017) or recruitment bias of participants with experience of those symptoms. Increasing the sample size and widening the sampling frame may provide greater insight into this issue. Finally, combining a similar survey approach with focus groups or qualitative interviews to gain a clearer understanding and expand on the pattern and description of pain and/or stiffness may provide further valuable insight.

It is important for health professionals, in particular first-line practitioners, to consider the possibility of a PD diagnosis when a patient presents with shoulder symptoms. The clinical reasoning process should carefully consider all presenting features when assessing patients with a painful and/or stiff shoulder to ensure an accurate diagnosis and, therefore, an appropriate management pathway is followed. As the results indicate, the majority of physiotherapist respondents are currently unaware of this early manifestation. Therefore, further education and professional development may be needed to avoid inappropriate investigations and treatment. The lack of understanding between shoulder pain and/or stiffness as an early symptom of PD and the other variables investigated within the study increases the need for education, as there are no other indicators that allude to the possibility of a PD

diagnosis. Following the delivery of education, repeating the survey in the future may also be valuable to determine whether the knowledge and awareness of physiotherapists on this topic changes over time.

CONCLUSION

This study provides important insight from both a patient and physiotherapist perspective into shoulder pain and/or stiffness as an early or initial symptom of PD. The study has identified a high prevalence of shoulder pain and/or stiffness as an initial symptom of PD and limited physiotherapist knowledge on this topic. As such, a key focus area for physiotherapy professional development has been identified. Increasing the knowledge and awareness of health professionals on this topic may lead to earlier and accurate diagnosis for PLWPD, which would facilitate appropriate treatment and reduce the costs associated with misdiagnosis and mismanagement. Although our results reflect an Australian perspective, arguably they could be generalised to other countries, including New Zealand, with similarities in population and provision of health care.

KEY POINTS

1. Almost one in 10 patients with Parkinson's disease report shoulder pain and/or stiffness as the initial symptom of Parkinson's disease.
2. Many patients with Parkinson's disease reported the onset of shoulder pain and/or stiffness within 5 years prior to diagnosis, without a past history of shoulder issues.
3. Physiotherapists have limited knowledge and awareness of shoulder pain and/or stiffness presenting as an early symptom of Parkinson's disease.

DISCLOSURES

No financial support was obtained for this study. There are no conflicts of interest which may be perceived to interfere with or bias this study.

PERMISSIONS

This study was approved by the Hunter New England Research and Ethics Committee (H-2019-0028) and co-registered with the University of Newcastle Human Research Ethics Administration (2018/ETH00631).

ADDRESS FOR CORRESPONDENCE

Dr Sarah Walmsley, School of Health Sciences, Faculty of Health and Medicine, The University of Newcastle, Newcastle, Australia.

Email: sarah.walmsley@newcastle.edu.au

ACKNOWLEDGEMENTS

The authors would like to thank both the PLWPD and physiotherapy participants who contributed their valuable time to complete the survey.

REFERENCES

- Aarsland, D., Creese, B., Politis, M., Chaudhuri, K.R., Ffytche, D.H., Weintraub, D., & Ballard, H. (2017). Cognitive decline in Parkinson's disease. *Nature Reviews Neurology*, 13(4), 217–231. <https://doi.org/10.1038/nrneuro.2017.27>
- Balash, Y., Korczyn, A.D., Knaani, J., Migirov, A.A., Gurevich, T. (2017). Quality-of-life perception by Parkinson's disease patients and caregivers. *Acta Neurologica Scandinavica*, 136(2), 151–154. <https://doi.org/10.1111/ane.12726>
- Bohingamu Mudiyansele, S., Watts, J. J., Abimanyi-Ochom, J., Lane, L., Murphy, A. T., Morris, M. E., & Iansek, R. (2017). Cost of living with Parkinson's disease over 12 months in Australia: A prospective cohort study. *Parkinsons Disease*, 5932675. <https://doi.org/10.1155/2017/5932675>
- Bridgewater, K. J., & Sharpe, M. H. (1996). Aerobic exercise and early Parkinson's disease. *Journal of Neurologic Rehabilitation*, 10(4), 233–241. <https://doi.org/10.1177/154596839601000403>
- Britt, H., Miller, G. C., Henderson, J., Bayram, C., Harrison, C., Valenti, L., Pan, Y., Charles, J., Pollock, A. J., Wong, C. & Gordon, J. (2016). *General practice activity in Australia 2015–16*. Sydney University Press. <https://hdl.handle.net/2123/15514>
- Broen, M. P. G., Braaksma, M. M., Patijn, J., & Weber, W. E. J. (2012). Prevalence of pain in Parkinson's disease: A systematic review using the modified QUADAS tool. *Movement Disorders*, 27(4), 480–484. <https://doi.org/10.1002/mds.24054>
- Buhman, C., Wrobel, N., Grashorn, W., Fruendt, O., Wesemann, K., Diedrich, S. & Bingel, U., (2017). Pain in Parkinson disease: A cross-sectional survey of its prevalence, specifics, and therapy. *Journal of Neurology*, 264, 758–769. <https://doi.org/10.1007/s00415-017-8426-y>
- Cleeves, L., & Findley, L. (1989). Frozen shoulder and other shoulder disturbances in Parkinson's disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 52(6), 813–814. <https://doi.org/10.1136/jnnp.52.6.813-b>
- Connolly, B. S., & Lang, A. E. (2014). Pharmacological treatment of Parkinson disease: A review. *JAMA*, 311(16), 1670–1683. <https://doi.org/10.1001/jama.2014.3654>
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). SAGE Publications.
- Daikeler, J., Bošnjak, M., & Lozar Manfreda, K. (2020). Web versus other survey modes: An updated and extended meta-analysis comparing response rates. *Journal of Survey Statistics and Methodology*, 8(3), 513–539. <https://doi.org/10.1093/jssam/szm008>
- Defazio, G., Berardelli, A., Fabbrini, G., Martino, D., Fincati, E., Fiaschi, A., Moretto, G., Abbruzzese, G., Marchese, R., Bonuccelli, U., Del Dotto, P., Barone, P., De Vivo, E., Albanese, A., Antonini, A., Canesi, M., Lopiano, L., Zibetti, M., Nappi, G., . . . Tinazzi, M. (2008). Pain as a nonmotor symptom of Parkinson disease: Evidence from a case-control study. *Archives of Neurology*, 65(9), 1191–1194. <https://doi.org/10.1001/archneuro.2008.2>
- Deloitte Access Economics. (2015). *Living with Parkinson's disease*. Retrieved from <https://shakeitup.org.au/wp-content/uploads/2011/07/Living-with-Parkinsons-27082015-FINAL.pdf>
- Dennis, S., Watts, I., Pan, Y., & Britt, H. (2018). The likelihood of general practitioners referring patients to physiotherapists is low for some health problems: Secondary analysis of the Bettering the Evaluation and Care of Health (BEACH) observational study. *Journal of Physiotherapy*, 64(3), 178–182. <https://doi.org/10.1016/j.jphys.2018.05.006>
- Flynn, A., Allen, N.E., Dennis, S., Canning, C.G., & Preston, E. (2019). Home-based prescribed exercise improves balance-related activities in people with Parkinson's disease and has benefits similar to a centre-based exercise: A systematic review. *Journal of Physiotherapy*, 65(4) 189–199. <https://doi.org/10.1016/j.jphys.2019.08.003>
- Ha, A. D., & Jankovic, J. (2012). Pain in Parkinson's disease. *Movement Disorders*, 27(4), 485–491. <https://doi.org/10.1002/mds.23959>
- Haddad, F., Sawalha, M., Khawaja, Y., Najjar, A., & Karaman, R. (2017). Dopamine and levodopa prodrugs for the treatment of Parkinson's disease. *Molecules*, 23(1), 40. <https://doi.org/10.3390/molecules23010040>
- Hauser, R. A., Lew, M. F., Hurtig, H. I., Ondo, W. G., Wojcieszek, J., & Fitzer-Attas, C. J. (2009). Long-term outcome of early versus delayed rasagiline treatment in early Parkinson's disease. *Movement Disorders*, 24(4), 564–573. <https://doi.org/10.1002/mds.22402>
- Hill, C. L., Gill, T. K., Shanahan, E. M., & Taylor, A. W. (2010). Prevalence and correlates of shoulder pain and stiffness in a population-based study: The North West Adelaide Health Study. *International Journal of Rheumatic Diseases*, 13(3), 215–222. <https://doi.org/10.1111/j.1756-185X.2010.01475.x>
- Hirsch, M. A., Van Wegen, E. E. H., Newman, M. A., & Heyn, P. C. (2018). Exercise-induced increase in brain-derived neurotrophic factor in human Parkinson's disease: A systematic review and meta-analysis. *Translational Neurodegeneration*, 7, 7. <https://doi.org/10.1186/s40035-018-0112-1>
- Ives, N. J., Stowe, R. L., Marro, J., Counsell, C., Macleod, A., Clarke, C. E., Gray, R., & Wheatley, K. (2004). Monoamine oxidase type B inhibitors in early Parkinson's disease: Meta-analysis of 17 randomised trials involving 3525 patients. *BMJ*, 329(7466), 593. <https://doi.org/10.1136/bmj.38184.606169.AE>
- Jankovic, J. (2008). Parkinson's disease: Clinical features and diagnosis. *Journal of Neurology, Neurosurgery & Psychiatry*, 79(4), 368–376. <https://doi.org/10.1136/jnnp.2007.131045>
- Madden, M. B., & Hall, D. A. (2010). Shoulder pain in Parkinson's disease: A case-control study. *Movement Disorders*, 25(8), 1105–1106. <https://doi.org/10.1002/mds.23048>
- Myall, D. J., Pitcher, T. L., Pearson, J. F., Dalrymple-Alford, J. C., Anderson, T. J., & MacAskill, M. R. (2017). Parkinson's in the oldest old: Impact on estimates of future disease burden. *Parkinsonism & Related Disorders*, 42, 78–84. <https://doi.org/10.1016/j.parkreldis.2017.06.018>
- Pagan, F. L. (2012). Improving outcomes through early diagnosis of Parkinson's disease. *American Journal of Managed Care*, 18(7), S176–S182.
- Riley, D., Lang, A. E., Blair, R. D., Birnbaum, A., & Reid, B. (1989). Frozen shoulder and other shoulder disturbances in Parkinson's disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 52(1), 63–66. <https://doi.org/10.1136/jnnp.52.1.63>
- Schenkman, M., Hall, D. A., Barón, A. E., Schwartz, R. S., Mettler, P., & Kohrt, W. M. (2012). Exercise for people in early- or mid-stage Parkinson disease: A 16-month randomized controlled trial. *Physical Therapy*, 92(11), 1395–1410. <https://doi.org/10.2522/ptj.20110472>
- Schrag, A., Horsfall, L., Walters, K., Noyce, A., Petersen, I. (2014). Prediagnostic presentations of Parkinson's disease in primary care: A case-control study. *The Lancet. Neurology*, 14(1), 57–64. [https://doi.org/10.1016/S1474-4422\(14\)70287-X](https://doi.org/10.1016/S1474-4422(14)70287-X)
- Stamey, W., Davidson, A., & Jankovic, J. (2008). Shoulder pain: A presenting symptom of Parkinson disease. *Journal of Clinical Rheumatology*, 14(4), 253–254. <https://doi.org/10.1097/RHU.0b013e3181826d43>
- Sveinbjornsdottir, S. (2016). The clinical symptoms of Parkinson's disease. *Journal of Neurochemistry*, 139(S1), 318–324. <https://doi.org/10.1111/jnc.13691>
- Valkovic, P., Minar, M., Singliarova, H., Harsany, J., Hanakova, M., Martinkova, J., & Benetin, J. (2015). Pain in Parkinson's disease: A cross-sectional study of its prevalence, types, and relationship to depression and quality of life. *PLoS One*, 10(8), e0136541. <https://doi.org/10.1371/journal.pone.0136541>
- Ya-Ting, C., Wen-Neng, C., Nai-Wen, T., Kuei-Yueh, C., Chih-Cheng, H., Chia-Te, K., Yu-Jih, S., Wei-Che, L., Ben-Chung, C., Chih-Min, S., Yi-Fang, C & Cheng-Hsien, L. (2015). Clinical features associated with frozen shoulder syndrome in Parkinson's disease. *Parkinson's Disease*, 2015, 232958. <https://doi.org/10.1155/2015/232958>

Appendix A

SURVEY FOR PATIENTS WITH PARKINSON'S DISEASE

These questions ask background information about you

- 1. In what year were you born? _____
- 2. What is your gender? Male Female Other
- 3. What is your postcode? _____
- 4. In what country were you born? _____
- 5. Do you identify as Aboriginal or Torres Strait Islander?
 Yes, Aboriginal
 Yes, Torres Strait Islander
 Yes, both Aboriginal and Torres Strait Islander
 No
- 6. Which response best describes your highest level of education completed?
 Did not complete high school
 School certificate (year 10)
 Higher school certificate (year 12)
 Certificate/diploma (TAFE)
 Bachelor degree
 Postgraduate
- 7. Do you have private health insurance?
 Yes No

These questions ask about your Parkinson's disease symptoms

- 8. How old were you when you were diagnosed with Parkinson's disease? _____
- 9. What was the first Parkinson's disease symptom you experienced? _____

- 10. Have you ever experienced shoulder pain and/or stiffness?
 Yes No

*If you answered **No** to the last question, you do not need to continue, and you have now completed the survey.*

*If you answered **Yes**, please continue.*

These questions ask about your shoulder symptoms

- 11. Did the shoulder pain and/or stiffness occur before your diagnosis of Parkinson's disease?
 Yes No (go to question 13)
 Unsure (go to question 13)

- 12. How long prior to your Parkinson's disease diagnosis did you experience pain and/or stiffness?

- 13. Do you have a past history of any shoulder problems, e.g. rotator cuff problem, arthritis?
 Yes No
If **yes**, please describe: _____

- 14. Have you seen a physiotherapist for your shoulder pain and/or shoulder stiffness?
 Yes No
- 15. If **yes**, what treatment did you receive from the physiotherapist for your shoulder?
Please tick all that apply.
 Education and advice Stretching exercises
 Taping Strengthening exercises
 Ice Home exercises
 Heat Massage
 Dry needling/acupuncture
 Other, please describe: _____

- 16. Did the physiotherapist refer you to someone else to review your pain and/or shoulder stiffness, e.g. another physiotherapist, a chiropractor, an orthopaedic surgeon?
 Yes No
If **yes**, please describe: _____

- 17. Have you had any treatment other than physiotherapy for your shoulder pain and/or stiffness, e.g. acupuncture, cortisone injection, surgery, other?
 Yes No
If **yes**, please describe: _____

- 18. Would you like to provide any further comments?

Thank you for completing this survey. Your time and contribution are greatly appreciated.

Appendix B

SURVEY FOR PHYSIOTHERAPISTS (FORMATTED INTO QUALTRICS)

- 1. What is your current primary/main physiotherapy work setting?
 Private practice Private hospital
 Public hospital
- 2. What is the postcode of the location of your primary/main physiotherapy workplace? _____
- 3. What is your gender?
 Male Female Other
- 4. How many years have you been practising as a physiotherapist?
 0-2 11-20
 3-5 21-30
 6-10 Over 30
- 5. What is your highest physiotherapy qualification?
 Graduate diploma Master's degree
 Bachelor's degree Doctorate
- 6. Are you an Australian Physiotherapy Association titled member?
 Yes No
*(Condition: **No** is selected. Skip to question 9)*
- 7. If yes, please indicate the national group to which your titling was awarded, e.g. musculoskeletal, sports, neurology.
- 8. Are you a fellow of the Australian College of Physiotherapists?
 Yes No
- 9. Do you see patients with shoulder pain and/or stiffness?
 Yes No
*(Condition: **No** is selected. Skip to question 13)*
- 10. If you do see patients with shoulder pain/stiffness, on average, how many new patients would you see in a month?
 0 11-15
 1-5 >15
 6-10
- 11. If you diagnose a patient with shoulder pain/stiffness, what is your typical management? Please select all that apply.
 Education and advice Dry needling
 Electrophysical agents Strengthening exercises
 Manual therapy Stretching exercises

- Referral to GP for further management, e.g. corticosteroid injection
- Referral for orthopaedic opinion
- Other, please specify:

- 12. If a patient doesn't respond to your usual management, what do you do? Please select all that apply.
 Manage with another physiotherapy option
 Discharge with no referral
 Discharge with exercises and advice
 Refer to another health professional, e.g. exercise physiologist, acupuncture
 Refer back to GP or medical officer in a hospital setting
 Other, please specify:

- 13. Before reading the information accompanying this questionnaire, were you aware that shoulder pain and/or stiffness is frequently an early symptom of Parkinson's disease?
 Yes No
*(Condition: **No** is selected. Skip to: Question 17)*
- 14. If you examine a patient with shoulder pain and/or stiffness, what factors of their presentation would make you suspect Parkinson's disease?
- 15. Would your management of shoulder pain/stiffness differ if you suspected Parkinson's disease?
 Yes No
*(Condition: **No** is selected. Skip to: Question 17)*
- 16. If you examine a patient with shoulder stiffness and suspect it may be due to Parkinson's disease, what is your management? Please select all that apply.
 Do a more detailed assessment, including assessment of any neurological symptoms
 Refer the patient to a neurological physiotherapist/ neurological support group/exercise group?
 Refer the patient to their GP
 Other, please specify:
- 17. Do you have any further comments that you think may be useful to the research team?

