Title: REVIEW: Falls Self-management Interventions for People with Parkinson’s: A Systematic Review

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Running Title: Falls self-management interventions for PwP

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## Abstract

### Background

Falls are common in Parkinson’s disease (PD). Increased involvement of people with Parkinson’s (PwP) in their care has been associated with enhanced satisfaction. Self-management programmes in other long-term conditions (LTCs) have led to improvements in physical and psychological outcomes. These have been more effective when targeted toward a specific behavior.

### Objective

This paper aimed to identify and review falls self-management interventions for PwP.

### Methods

A systematic review was conducted. Electronic databases were searched in June 2018. Primary research studies (any design) reporting the delivery of falls self-management interventions to PwP were included. Data was extracted from each article and synthesised narratively.

### Results

Six articles were identified, relating to five different self-management interventions. All described a self-management intervention delivered alongside physiotherapy. Intervention delivery was through either group discussion (n=3) or falls booklets (n=3). Interventions were often incompletely described; the most common components were information about the condition, training/ rehearsal for psychological strategies and lifestyle advice and support. Arising from the design of articles included the effects of self-management and physiotherapy could not be separated. Three articles measured falls, only one led to a reduction. Four articles measured quality of life, only one led to improvement. No articles assessed skill acquisition or adherence to the self-management intervention.

### Conclusions

Few falls self-management interventions for PwP have been evaluated and reported. The components of an effective intervention remain unclear. Given the benefits of self-management interventions in other LTCs, it is important that falls self-management interventions are developed and evaluated to support PwP.

Keywords: Parkinson disease; Accidental falls; Patient Education as topic; Self care; Review

## Introduction

Falls are common in Parkinson’s disease (PD), with two thirds of people with Parkinson’s (PwP) falling each year compared to one third of the general older population [1]. Falling often leads to a fear of falling and a decline in physical activity, which is associated with negative outcomes including a decline in both physical function and quality of life (QOL) [2,3]. Falling in Parkinson’s is multifactorial; specific risk factors include freezing of gait and postural instability but recurrent falls are more likely among those with cognitive impairment [4,5]. The prevalence of cognitive impairment rises with increasing patient age and disease duration but mild dysfunction has been reported in 24% of newly diagnosed PwP [6,7]. The majority of PwP live in their own homes helped by family members, ‘informal caregivers’, who provide vital physical, emotional and social support [4,8]. Caregivers of PwP often feel unprepared and unsupported in this role, and the onset of falling has been associated with increased caregiver burden [9,10].

Systematic reviews of physiotherapy interventions for falls have reported inconclusive results, which may relate to the nature of the studies included. Reviews of physiotherapy interventions have been based upon studies of predominantly low-moderate methodological quality with heterogeneity of interventions and outcomes measured [11–13]. Whilst a recent systematic review of physiotherapy interventions for falls conducted by Shen et al. reported a reduction in fall rate, the effect size was small and outcomes from individual studies were mixed [12]. Earlier reviews conducted by Allen et al. and Tomlinson et al., reported no effect of physiotherapy on fall rate or the proportion of fallers respectively [11]. In Shen et al., the greatest benefits were observed in association with facility based training [12]. By design, these studies may exclude PwP with greater disease severity or cognitive impairment, as travel may be more cumbersome. Rehabilitative interventions may be less effective in those with more advanced PD, where falling is more common [16]. Similarly, in a recent large multi-centre randomized controlled trial (RCT), a four month high-intensity structured exercise programme did not lead to improvements in fall rate or QOL in people with mild to moderate dementia or their caregivers [17].

The review of physiotherapy interventions by Tomlinson et al. reported a lack of effect on both fear of falling and quality of life [11]. Whilst a review of occupational therapy based interventions for PwP reported a positive short-term effect on QOL, this was based upon the results of three small studies, which each had no more than 20 participants [16]. This finding was not replicated in two subsequent large RCTs of occupational therapy, where the majority of participants had mild-moderate PD, the very group amongst whom rehabilitative interventions have been proposed to be more effective [14,17,18].

PwP and their caregivers have expressed a wish for enhanced involvement and participation in their care, which has been associated with enhanced patient satisfaction [8,25,26]. Self-management has been proposed as a potential strategy to help PwP and their caregivers to identify and address problems relating to how Parkinson’s affects them [27]. Self-management can be broadly defined as increased responsibility or confidence of an individual in managing a long-term condition (LTC) [18]. Self-management programmes in LTCs such as diabetes, stroke and Chronic Obstructive Pulmonary Disease (COPD) have led to improvements in physical and psychological outcomes [19–23]. Similarly, promoting active patient engagement, has been shown to be cost effective by improving quality of care and medical outcomes in older patients with multimorbidity [24].

The majority of self-management programmes are based on Bandura’s self-efficacy theory which hypothesises that an individual’s self-perceived ability to perform a task, or to manage a situation, is directly related to their subsequent likelihood of success [18]. For an individual to self-manage a LTC they might require training in medical, behavioral and emotional techniques. Arising from the heterogeneity of falls in PD, PwP and their caregivers are likely to differ in what they require to for effective self-management [4,5]. Important factors might be knowledge of the contributing risks to falls and skills and confidence in how to modify them, and understanding when and who to contact if difficulties arise.

A 2017 integrative review of self-management programmes for PwP to support any aspect of PD concluded that there was insufficient evidence to support their effectiveness [28]. Following self-efficacy theory, self-management programmes in other LTCs have been more effective when targeted toward a specific behavior as opposed to providing generic advice and support [18,29]. In this paper we aimed to systematically identify and review falls self-management interventions for PwP, and if possible, assess their efficacy for improving patient and caregiver outcomes, QOL and psychological outcomes. Such information will be beneficial to inform the development of falls self-management interventions for PwP in research and routine clinical practice.

## Materials and Methods

This review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines [30]. The review protocol was registered on PROSPERO, CRD42017052585.

### Searching strategy and identification of articles

Searches were conducted in June 2018. Searches aimed to locate all papers relating to self-management in PD. A sensitive and inclusive searching strategy using Medical Subject headings (MeSH) and key free text terms pertaining to (i) PD and (ii) self-management was developed. Animal studies were excluded and the search was limited to studies published since the emergence of the concept of self-management within the literature (1986 onwards) [19]. The search was developed in MEDLINE and adapted for use in **EMBASE, CINAHL, AMED, PSYCHInfo and Science Citation Index Expanded (Web of Science)** (Supplementary Table S1). Given the heterogeneity of interventions that may support self-management in LTCs, we did not stipulate that authors needed to use the term ‘self-management’ [19–22]. The search strategy contained no falls-related terms to allow identification of studies where falling was only discussed in the full text. **Additional searches were made in clinical trials registers. The** grey literature was searched at www.opengrey.eu.

Articles were eligible for inclusion where they reported interventions aimed to improve falls self-management in PwP. Studies were included regardless of design. **A broad definition of self-management was used; s**tudies that aimed to increase the responsibility or confidence of PwP in managing falls. **Articles were excluded where the intervention consisted of physiotherapy alone.**

Multi-modal interventions were included where one component aimed to support self-management of falling. **No restrictions on language were applied.**

After removal of duplicates, article titles were screened by CO for relevance. CO and KI independently screened all abstracts for eligibility. Full texts of all potentially relevant articles were reviewed for relevance and discrepancies were resolved through mutual discussion. **Reference lists of relevant articles were screened. Figure 1 depicts the search results and inclusion/exclusion process.**

### Data analysis and assessment of study quality

Self-management programmes are often complex and multi-faceted. Complex interventions are comprised of multiple interacting components, with additional dimensions to include heterogeneity of those delivering or receiving the intervention [31]. In the wider LTC literature, inadequately detailed reporting of the content and delivery of complex interventions, and the lack of a shared language for describing their components, has been identified as a barrier to drawing clear conclusions about what works and why and to wider implementation [32–34]. The ‘Practical Reviews in Self-management Support’ (PRISMS) taxonomy was used to characterize the self-management component of each intervention [32]. This tool (Table 1) details 14 components that a self-management programme might contain and has successfully been used to identify the key features of self-management interventions to support patients with diabetes, heart failure, asthma, Chronic Obstructive Pulmonary Disease (COPD) and cancer [26,28].

**CO extracted data from the selected articles into a predefined database, with all content confirmed by KI. Authors of all included articles were contacted for clarification or to request additional information.** CO and KI independently appraised each included article using The Joanna Briggs Institute (JBI) Randomized Controlled Trials Critical Appraisal Checklist [35]. T**he analysis took the form of a narrative synthesis**.

## Results

### Article selection and quality appraisal

Of the 11693 articles identified, 48 full text articles were screened and four met the eligibility criteria for inclusion. A further two articles were identified through reference screening.

A conference abstract was identified that described the development of a falls self-management guide for PwP to be delivered alongside physiotherapy [36]. The author was contacted; no details of the participants or how the intervention was implemented or evaluated were available, and it was excluded from our review.

No additional records were identified through searches of the grey literature and clinical trials registers. Thus six articles were included in the review (Figure 1).

Articles scored between 7-9 out of 13 possible quality criteria (Supplementary table S2).

### Article Characteristics

### Study design

The included articles comprised five research papers and one thesis (Table 2). All reported RCTs. Two articles were based on the same population and intervention; the participants in White et al. were a subsample of those from Tickle-Degnen et al. but different outcome measures were reported [37,38].

No articles were identified that studied the effect of a falls self-management intervention in isolation. Each article evaluated the effect of a self-management intervention alongside a physiotherapy intervention. Canning et al. studied the effect of an intervention that contained physiotherapy and self-management, and compared it to self-management alone [39]. The other five articles studied the effect of an intervention that contained physiotherapy and self-management and compared it to a control which did not contain either of these constituents [37–41].

### Setting and Participant characteristics

Trials were conducted between 2003 and 2016; three in Australia and three in the USA. The total number of participants was 718 (range 27 to 231 in each study). Participants were all PwP, no interventions included caregivers. Mean age varied from 58 to 71.4 years; mean time from diagnosis was 5.1 to 8.8 years. In five of six articles, the majority of participants had a Hoehn and Yahr stage of less than three, indicating reduced fall risk [38,40–42]. All articles excluded those with cognitive impairment. In the three data sets that reported baseline falls, 55 to 78% had fallen within the last year [39–41].

### Intervention delivery

Self-management interventions were delivered through either group discussion or the provision of falls booklets. In each of the group interventions, falls self-management was embedded within a programme that targeted self-management of a range of PD related difficulties [37,38,42]. In the three articles containing falls booklets, falls was the key target of the intervention [39–41].

#### Group discussion

Three articles, evaluating two different interventions described physical therapist facilitated group discussion of self-management alongside physiotherapy [37,38,42]. Peteet assessed the effect of a weekly physical exercise and self-management education programme compared to exercise alone [42]. The intervention was delivered over six weeks by a physical therapist and contained weekly individualized education sessions. Only week four of the intervention focused on falls, where a 20-25 minute therapist led discussion on falls was delivered, which included falls prevention, safety and strategies to minimize falls. Participants were encouraged to develop and complete exercise-related action plans. Tickle-Degnen et al. and White et al. assessed the effect of a weekly group-based self-management rehabilitation programme delivered over six weeks by a physical therapist, compared to social group sessions that contained no self-management or falls-based content [37,38]. Each session consisted of one hour of physiotherapy and speech therapy followed by a 30 minute group discussion, which included the topics ‘preventing falls’, ‘strategies to improve walking’, ‘relaxation, stress management’ and ‘benefits of exercise’.

#### 2. Falls booklets

Three articles, Canning et al., Morris et al. 2015 and Morris et al. 2017, contained a self-management component based upon the same the falls booklet *‘Don’t fall for it. Falls can be prevented!’*, which was delivered alongside physiotherapy [39–41,43]. This 32 page booklet is aimed toward all older people at risk of falling and contains no PD-specific information [39–41,43]. In Canning et al., participants in both arms of the study were given a copy of the booklet and no verbal falls education was delivered; only the physiotherapy component differed between the intervention and control arms [39]. In Morris et al. 2015 over eight weeks, and Morris et al. 2017 over six weeks, weekly falls education was delivered by a physical therapist based upon the content of the booklet and participants were given a copy to take away [40,41]. In Morris et al. 2015 education was delivered over eight weeks; it was unclear whether it was individualized. In Morris et al. 2017 education was delivered over six weeks and was individualised to participants. The comparator groups in both Morris et al. 2015 and Morris et al. 2017 took part in weekly non-falls education sessions; in Morris et al. 2017 participants also received a non-self-management-based falls information sheet to take away [41].

### Analysis of Self-management Components of the Interventions

Table 1 summarises the self-management intervention components reported in each study based on the PRISMS taxonomy. Description of the self-management component was very brief; articles described them in an average of 60 words [37–41]. Additional information was received from three authors [40–42]. Through the citations provided, we were able to obtain and directly review the falls booklet utilized within three of the articles [39–41,43].

#### Information about the condition and/or its management

A fundamental part of self-management is arming patients with appropriate information about the condition and/or its management. This component was present in four of six articles. However, the topics, amount and presentation of information differed. Peteet provided participants in both trial arms with written information about PD, with those in the intervention arm also receiving information about falls [42]. In Tickle-Degnen et al and White et al, it is unclear whether participants received any information specific to PD or to falling [37,38]. The booklet utilized within three articles covers a wide breadth of falls-related topics, including potential aetiologies and different management strategies [43].

#### Training/ rehearsal for everyday activities

Another key component of a self-management intervention is learning and practicing behaviors and skills that are relevant for living with the condition. All articles delivered this component through physiotherapy strategies such as training with transfers, cueing strategies and movement strategy training, which includes training for functional tasks [37–42]. Five articles delivered this component through self-management strategies. Although the group discussions delivered by Tickle-Degnen et al and White et al, contained information about day to day activities such as strategies to improve dressing and walking, it is unclear whether these were falls-related [37,38]. The booklet used within three articles encourages users to ask for help from others if they consider a task to be high risk and to plan ahead [38,43].

#### Training/ rehearsal for psychological strategies

Self-management interventions often facilitate the development of psychological strategies such as the ability to re-frame symptoms, problem-solve and set personal goals. This component was present in all articles reviewed. The interventions that contained group discussion (Peteet et al., Tickle-Degnen et al. and White et al.) taught and encouraged participants to problem-solve and to develop realistic action plans in collaboration with a physical therapist [37,38,42]. However, it is unclear whether these action plans were falls-related, with no details provided surrounding their implementation. The booklet used within three articles has a page to develop action plan, but the interventions based upon this booklet did not appear to provide participants with training to complete these [39–41,43].

#### Lifestyle advice and support

Self-management interventions often contain advice about health and lifestyle; this was included within five of six of the articles. In the group sessions within Tickle-Degnen et al. and White et al., participants discussed the ‘Benefits of exercise’. The booklet utilized within three articles promotes a healthy lifestyle, including the importance of physical activity and dietary advice [39–41,43].

#### Social Support

All three articles that provided group discussion led by physical therapist provided social support [37,38,42]. Peteet actively encouraged group interaction; participants were asked to identify a ‘buddy’ for support although this appeared to be for exercise promotion and not for falls management [42]. No social support component was provided in the three articles that utilized the falls booklet [39–41].

#### Other components

Self-management interventions may contain regular clinical review and monitoring of the participant’s condition with feedback. Whilst provided within Peteet, these components were targeted toward exercise and not falling. In additional to the components described above, the booklet utilized within three articles supports falls self-management through providing (i) information about available resources, (ii) training to communicate with healthcare professionals to facilitate shared decision-making, and (iii) training/ rehearsal for practical self-management through teaching common strategies to reduce fall risk in the home [39–41,43].

Further components that the PRISMS taxonomy suggests may be contained within a self-management intervention, but were not included within any of the articles, were (i) individualized action plans prepared by a healthcare professional, (ii) practical support with adherence, (iii) provision of equipment, and (iv) easy access to further advice and support.

### Outcome measures

All articles assessed the effect of the intervention as a whole (Table 3). No articles separated the effect of the self-management component from the physiotherapy component, or assessed skill acquisition or adherence to the self-management component.

#### Falls outcomes

The three articles where the self-management component was based upon the falls booklet reported falls [39–41]. In Morris et al. 2015 participants fell less over 12 months when they received physiotherapy and self-management versus no physiotherapy or self-management [40]. However, no improvement was seen in the total number of participants who fell in Canning et al., Morris et al. 2015 or Morris et al. 2017 [39–41]. Morris et al. 2015 and Morris et al. 2017 found no difference in the number of multiple fallers, with combined physiotherapy and self-management versus no physiotherapy or self-management. Sub analysis in Canning et al. found a 69% reduction in falls in those with less advanced PD who received physiotherapy and self-management versus self-management alone [39]. Articles based on group discussion did not report falls outcomes

Only Canning et al. assessed fear of falling, which was measured through the Falls Efficacy Scale- International scale, which assesses concerns about falling in 16 different circumstances [44]. Scores significantly improved at six months in participants who received physiotherapy and self-management versus self-management alone [39].

#### Quality of Life (QOL)

Four articles assessed QOL. Tickle-Degnen et al. reported that combined physiotherapy and self-management was associated with significant improvement in health-related QOL (HRQOL) measured by Parkinson’s Disease Questionnaire 39 (PDQ39) at programme end at six weeks when compared to the control arm; improvement persisted at six months [38]. The three studies whose self-management component was based upon the falls booklet produced inconsistent results regarding QOL. In Morris et al. 2015, when compared to no physiotherapy or self-management, one intervention arm (progressive resistance and strength training plus self-management) was associated with an improvement in QOL as measured by PDQ39 but no change was observed in EuroQol 5 Dimensions Visual Analogue scale (EQ-5D VAS); in the other intervention arm (Movement strategy training plus self-management) no improvements were seen in either PDQ39 or EQ-5D VAS [40]. The combined physiotherapy and self-management intervention in Morris et al. 2017, was not associated with improvements in QOL when compared to no physiotherapy or self-management [41]. Canning reported significant improvement in Short-Form Six-Dimension (SF-6D) in participants who received physiotherapy and self-management compared to self-management alone; however, no change was observed in relation to either PDQ39 or the mental and physical sub scores of Short-Form 12 (SF-12) [39].

#### Other outcome measures

Four articles reported various physical activity outcomes [38–40,42]. Peteet, Morris et al. 2015 and White et al. found no statistical difference in physical activity outcome measures in participants who received each of the respective physiotherapy and self-management interventions compared to no physiotherapy and self-management [38,40,42]. Canning et al. reported improvement in the short physical performance battery and sit to stand in participants who received physiotherapy and self-management compared to self-management alone, but no improvement was seen in a number of other measures including exercise hours/ week [39].

Two articles collected Unified Parkinson’s disease rating scale (UPDRS) data. Morris et al. 2015 reported significant improvement in the activities of Daily Living (ADL) component of UPDRS, but not the motor component of the UPDRS in participants who received physiotherapy and self-management versus no physiotherapy or self-management [40]. Morris et al. 2017 reported no change in UPDRS with physiotherapy and self-management versus no physiotherapy and self-management [41].

Canning et al. reported adverse outcomes related to the physiotherapy component of the intervention; two participants fell whilst exercising at home. No studies reported adverse outcomes relating to the self-management component.

## Discussion

This is the first attempt to systematically review the literature on falls self-management interventions for PwP. Other reviews have begun to explore more generic self-management interventions to support PwP [28]. Despite a thorough and systematic search, few relevant studies were identified, allowing us to conclude that this is not a well-researched area. All of the articles included studied the effect of a self-management intervention, comprised of either group discussion or a falls booklet, alongside a physiotherapy intervention. Self-management was often not the main focus of the intervention and was incompletely described. Articles displayed considerable variation in outcomes measured.

### Methodological comments

All articles were of at least moderate quality. However, participants enrolled into studies were not representative of the range of PwP who fall, typically recruiting those with lower Hoehn and Yahr scores for example, and two articles studied the effect of the same intervention on the same cohort of participants. All articles excluded those with cognitive impairment, yet this group are at heightened risk of falling and its negative physical and psychological outcomes [4]. No articles included caregivers, who play a pivotal role in falls management [4,8]. Including caregivers in future research programmes may facilitate the inclusion of PwP with cognitive impairment, and improve caregiver outcomes.

Whilst the articles included a wide breadth of self-management strategies, these were often incompletely described, as has been identified in previous reviews of self-management interventions [33]. It is unclear whether the interventions delivered self-management as planned. Whilst multifaceted interventions may be more likely to benefit older people who fall, all intervention components should be well described to allow for them to be identified and replicated [31,45–47].

Key attributes that an individual requires to effectively self-manage a LTC are problem-solving, decision-making and goal setting [18]. None of the articles included within this review studied the effect of an intervention that clearly taught and promoted all three of these skills. Individuals also require information specific to their needs; however, in only one article was the intervention individualized to participants [18,41]. Providing a heterogeneous population with generic information can lead to information overload and user disengagement [39–41,43,48]. Future falls self-management programmes for PwP should explore tailoring of information to participants’ needs to increase the likelihood of adherence and long-term behavioral change [19,49].

### Impact of self-management programmes on falls and other clinical outcomes

All articles assessed the effect of physiotherapy and self-management in combination, making it impossible to draw firm conclusions about the specific contribution of falls self-management from the studies conducted so far.

In the three articles where falls outcomes were measured, only one recorded a reduced rate of falls, and none showed a reduction in the number of fallers [39,40,50]. Given that current evidence for rehabilitation interventions to reduce falls is inconclusive, the effect of self-management on falls remains unclear. Only Canning et al. 2015 measured fear of falling, however, as only the physiotherapy component differed between the intervention and comparator groups, the effect of self-management on fear of falling remains unexplored [39].

Most articles measured QOL but only the intervention studied by Tickle-Degnen et al., which contained group discussion and education to problem-solve and develop action plans, led to an improvement [38]. Group-based self-management programmes have previously been shown to provide social support and psychological benefit [51]. However, future researchers should consider their acceptability to participants with reduced mobility, where travel may be difficult, and explore the impact of programme end, which can lead to feelings of isolation [51].

No articles measured self-management outcomes such as applicable knowledge or independence, which are considered important by those with LTCs [52]. It is impossible to tell whether and to what extent PwP engaged with the self-management components. Future self-management programmes should look to include process evaluation measures such as acceptability, adherence and engagement; mixed methods are likely to be useful [53].

## Conclusion

Overall, the scarcity of published research, plus the nature of the studies to date, have made it impossible to draw any firm conclusions about the overall efficacy of falls self-management interventions for PwP, or to identify the important components of these interventions.

Within the articles included in this review, it is unclear whether interventions were targeted toward PwP who had experienced falls, and information was rarely individualized to participants. Future studies of programmes of falls self-management interventions may benefit from targeting those whom falls management is most critical, to include PwP with a history of falls, fear of falling and/or cognitive impairment, and caregivers.

Given the limitations of other interventions to support falling in PwP, and the benefits seen in self-management programmes in other LTCs, it is important that effective falls self-management programmes are developed and evaluated to support PwP.

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## Conflict of Interest

The Authors have no conflict of interest to report.

## Supplementary Material

Supplementary table S1 outlines the searching strategy used.

Supplementary table S2 outlines the quality appraisal of the included studies.

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## Tables

Table 1 Practical Reviews in Self-management Support (PRISMS) Self-management Components of the Interventions.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| PRISMS taxonomy component | Peteet [42] | Tickle Degnen et al. [38] | White et al. [37] | Canning et al. [39] | Morris et al. 2015 [40] | Morris et al.2017 [41] |
| A1. Information about the condition and/or its management | ✓ |  |  | ✓ | ✓ | ✓ |
| A2. Information about available resources |  |  |  | ✓ | ✓ | ✓ |
| A3. Provision of/ agreement on specific clinical action plans and/or rescue medication |  |  |  |  |  |  |
| A4. Regular clinical Review | ✓ |  |  |  |  |  |
| A5. Monitoring of condition with feedback | ✓ |  |  |  |  |  |
| A6. Practical support with adherence (medication or behavioral) |  |  |  |  |  |  |
| A7. Provision of equipment |  |  |  |  |  |  |
| A8. Provision of easy access to advice or support when needed |  |  |  |  |  |  |
| A9. Training/ rehearsal to communicate with health care professionals |  |  |  | ✓ | ✓ | ✓ |
| A10. Training/ rehearsal for everyday activities |  | ✓ | ✓ | ✓ | ✓ | ✓ |
| A11. Training/ rehearsal for practical self-management.  Includes skill acquisition |  |  |  | ✓ | ✓ | ✓ |
| A12. Training/ rehearsal for psychological strategies  Includes action planning and goal setting | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| A13. Social support | ✓ | ✓ | ✓ |  |  |  |
| A14. Lifestyle advice and support  Includes advice about exercise and a healthy diet |  | ✓ | ✓ | ✓ | ✓ | ✓ |

Table 2 Characteristics of Articles Included in the Review.

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Article authors and year  Study design | Participants | | | | | | Intervention including Self-Management | | Comparison Intervention | |
| Number | Mean age (SD) | H+Y (%) | Mean years since diagnosis (SD) | Mean MMSE (SD) | Fallen in the last year | Description | 1. Frequency and duration  2. Setting  3. Delivered by | Description | 1. Frequency and duration  2. Setting  3. Delivered by |
| Peteet [42]  RCT | 27 | Intervention 58 (7.0)  Control 63 (9.5) | H+Y II 74%  H+Y III 26% | Intervention  8.8 (3.9)  Comparison 7.0 (4.4) | All ≥25 | No data | 1. Behavioural based self-management education programme. Week 4 contained a 20-25 minute group discussion about fall prevention and safety. 2. Exercise programme | 1. 1.5hrs/ week for 6 weeks 2. Hospital 3. Therapist with physical therapy assistance | Exercise programme only | 1. 1.5hrs/ week for 6 weeks 2. Hospital 3. Therapist with physical therapy assistance |
| Tickle-Degnen et al. [38]  3 arm RCT | 117 | 66.3 (9.0) | H+Y <III 84%  H+Y III 16% | 7.1 (5.7) | 29.3 (1.0) | No data | Intervention 1 and 2  Twice weekly ‘Group clinic sessions’   1. Motion, flexibility and strength exercises (25 minutes) 2. Speech exercises (10 min) 3. Daily function training examples (15 min) 4. Gait training (10 min) 5. Group discussion (30min), including ‘preventing falls’   Intervention 2 only  Additional weekly transfer sessions | Group sessions:   1. 2x1.5 hr/week for 6 weeks 2. Hospital 3. Physical therapist   Transfer sessions   1. 1.5hr/week for 6 weeks 2. Home 3. Physical therapist | ‘Social group sessions’ including ice breaker activities, refreshments and conversation | 1. 1.5 hr/week for 6 weeks 2. Hospital 3. Physical therapy student |
| White et al. [37]  3 arm RCT | 74 AM data  108 2MWT data | Intervention 65.6 -68.2  Control 65.4- 66.0 | H+Y <III 85%  H+Y III 15% | Intervention 5.1- 6.9  Comparison 5.6- 6.7 | No data | No data | *[as per Tickle-Degnen et al. [38]]* | | | |
| Canning et al. [39]  RCT | 231 | Intervention 71.4 (8.1)  Comparison 69.9 (0.3) | Intervention  H+Y II 30%  H+Y III 67%  H+Y IV 3%  Control  H+Y II 35%  H+Y III 60%  H+Y IV 5% | Intervention 7.5 (5.8)  Comparison  8.3 (6.0) | Intervention 28.6 (1.5)  Control 28.7 (1.4) | 78 % | Physiotherapy  Progressive balance and lower limb strengthening exercises and cueing strategies (PD-WEBB), exercise classes and physical therapist home visits  PLUS  Education:  Received the booklet ‘Don’t fall for it, falls can be prevented’. | 1. Over 6 months: 2. PD-WEBB 40-60 mins 3x/week; 3. Exercise class monthly 4. 2-4 home visits 5. PD-WEBB and exercise class at the hospital. 6. Physical therapist led | Received the booklet ‘Don’t fall for it, falls can be prevented’. | |
| Morris et al. 2015 [40]  3 arm RCT | 210 | 67.9 (9.6) | H+Y <III 59%  H+Y III 30%  H+Y IV 11% | 6.7 (5.6) | 28.2 (1.8) | 55% | Physiotherapy  EITHER:  Movement Strategy Training (MST)  OR  Progressive resistance strength training (PRST)  PLUS  Education  Based on the booklet ‘Don’t fall for it. Falls Can be prevented.’ Elements explained to each participant and given a copy to take away | 1. Physiotherapy:2 hrs/ week for 8 weeks plus home practice session. Falls education delivered weekly. 2. Hospital 3. Physical therapist led | Life skills program.  Included social activities, practical advice, information sessions and group discussions but no falls content. | |
| Morris et al.  2017 [41]  RCT | 133 | 71 (9) | H+Y<III 66%  H+Y III 29%  H+Y IV 5% | Unknown | 28.3 (1.6) | 55% | Physiotherapy  Progressive resistance strength training  Movement strategy training  PLUS  Education  Individualized falls education based on the booklet ‘Don’t fall for it, Falls can be prevented’. Participants given a copy to take away. | 1. Physiotherapy: 2 hrs/ week for 6 weeks.   Falls education delivered weekly.   1. Home 2. Physical therapist led | Life skills program.  Weekly guided education and discussion sessions followed by self-directed homework. No falls content.  A standard help sheet from Parkinson’s Victoria and a generic falls information sheet. | |

Abbreviations:hrs=hours; H+Y= Hoehn and Yahr staging; mins=minutes; MMSE= Mini Mental State Examination score; RCT= Randomized controlled trial SD= Standard Deviation

Table 3 Outcomes of Articles Included in the Review.a

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Article | Statistical comparisons made | | Falls Outcomes | FES-I | QOL | | Mood | Other Outcomes measured | |
| Summary of Intervention containing self-management | Summary of comparator |  |  |
| Outcome | Results | Outcome | Results |
| Peteet [42] | Self-management plus exercise programme | Exercise Programme |  |  |  |  |  | Physical Activity Scale for the elderly (PASE), TUG, FRT | No change at 6 weeks or at 12 weeks |
| Tickle-Degnen et al. [38] | Self-management plus physiotherapy | Social Group sessions  (No self-management or physiotherapy) |  |  | **PDQ-39** | **Improvement post intervention and at 6 month follow-up  (p =0.02)** |  |  |  |
| White et al. [37] | Self-management plus physiotherapy | Social Group sessions  (No self-management or physiotherapy) |  |  |  |  |  | **Total time spent walking and number of walking periods** | **No change** |
| Canning et al. [39] | Self-management plus physiotherapy | Self-management | **No difference in rate of falls** orin the number of fallers over 12 months**.** | Improvement post intervention (p<0.01) | SF6D | Improvement post intervention (p<0.01) | Significant improvement in positive affect score post intervention (p<0.05) | Short physical performance battery and sit to stand. | Improvement post intervention (p<0.05) |
| SF-12 physical, SF-12 mental, PDQ39 | No change | Mean knee extensor strength, co-ordinated stability test, 4m fast walk test, FOG, Exercise hr/wk, ADL hr/day | No change |
| Morris et al. 2015 [40] | Self-management plus physiotherapy (MST or PRST) | Life Skills Programme  (No self-management or physiotherapy) | **Reduced rate of falls over 12 months associated with MST (P<0.05) and PRST (P<0.01)**  No difference in number of fallers or multiple fallers over 12 months. |  | PDQ39 | PRST: Improvement at 12 months  (p<0.05)  MST: no change |  | UPDRS ADL | MST and PRST: Improvement at 12 months (p<0.01). |
| UPDRS Motor | MST: Improvement at 12 months (p<0.05) |
| Walking speed (derived from 6m walk test) and TUG | No change |
| EQ-5D VAS | MST and PRST: no change |
| Morris et al.  2017 [41] | Self-management plus physiotherapy | Life Skills Programme (No self-management or physiotherapy) | **No difference in the rate of falls** or number of fallers or multiple fallers over 12 months. |  | PDQ39 | No change |  | UPDRS | No change |
| EuroQol-5D | No change |

Abbreviations:ADL= Activities of Daily Living; EQ-5D VAS= EuroQol 5 Dimensions Visual Analog Scale; FES-I= Falls Efficacy Scale International; FOG= Freezing of gait; FRT= Functional Reach Test; MST**=** Movement Strategy Training; PASE= Physical Activity Scale for the elderly; PDQ39= Parkinson’s Disease Questionnaire 39; PRST= Progressive resistance strength training; SF-6D= Short form 6 dimension; SF-12 physical/ SF-12 mental= Short form 12 physical/ short form mental component summary; TUG= Timed up and Go; UPDRS= Unified Parkinson’s Disease Rating Scale

a Primary outcomes in bold (Peteet did not define which outcome was the primary outcome)

## Figures

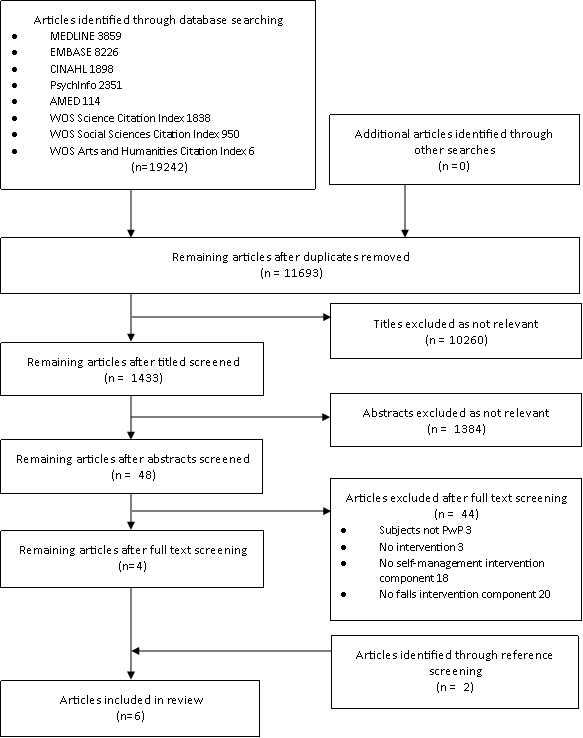


Figure 1 Preferred Reporting Items for Systematic Reviews and meta-analyses (PRISMA) diagram detailing the search process undertaken in this review.

Abbreviations: n= number; PRISMA= Preferred Reporting Items for Systematic Reviews and Meta-analyses; PwP= People with Parkinson’s

## Supplementary Data

## Supplementary table S1: MEDLINE Searching strategy.a

|  |
| --- |
| 1. Parkinson Disease/ |
| 2. Parkinson\*.mp,hw. |
| 3. 1 or 2 |
| 4. Patient education as topic/ |
| 5. exp Consumer health information/ |
| 6. educat\*.tw. |
| 7. exp self care/ |
| 8. (self adj (assess\* or care or help or manag\* or monitor\* or efficacy or evaluat\* or concept or direct\*)).tw. |
| 9. exp self concept/ |
| 10. self evaluation/ |
| 11. exp adaptation psychological/ |
| 12. psychological adjustment/ |
| 13. (Psychologic\* adj (adjust\* or adapt\*)).tw. |
| 14. social learning theory.tw. |
| 15. exp health behavior/ |
| 16. consumer behavior/ |
| 17. behavior therapy/ |
| 18. (behav\* adj (adapt\* or alter\* or chang\* or therap\*)).tw. |
| 19. attitude to health/ |
| 20. health knowledge, attitudes, practice/ |
| 21. coping behavior/ |
| 22. (cope or copes or coping).tw. |
| 23. exp decision making/ |
| 24. (decision\* adj (making or made)).tw. |
| 25. (inform\* adj (choice\* or decision\*)).tw. |
| 26. problem solving/ |
| 27. (problem adj solving).tw. |
| 28. ((patient\* or consumer\* or client\* or participant\*) adj (monitor\* or adjust\*)).tw. |
| 29. "power (psychology)"/ |
| 30. empower\*.tw. |
| 31. ((improv\* or increas\*) adj2 confiden\*).tw. |
| 32. social support/ |
| 33. (social adj (support\* or network\* or engagement\*)).tw. |
| 34. "Patient Satisfaction"/ |
| 35. disease management/ |
| 36. 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 |
| 37. 3 and 36 |
| 38. animal/ |
| 39. human/ |
| 40. 38 not (38 and 39) |
| 41. 37 not 40 |
| 42. limit 41 to yr="1986- current" |

a Medical Subject headings (MeSH) and key free text terms relating to:  
Parkinson’s disease (search terms 1-3) and self-management (search terms 4-36) to identify studies relating to Parkinson’s and self-management (search term 37).   
Animal studies were identified and excluded (search terms 38-41).   
Limitations applied to identify studies from 1986 onwards (search term 42).

## Supplementary table S2: Quality Appraisal of Included Studies.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Question | Peteet [42] | Tickle-Degnen et al. [38] | White et al. [37] | Canning et al. 39] | Morris et al. 2015 [40] | Morris et al. 2017 [41] |
| Was true randomization used for assignment of participants to treatment groups? | 0 | 1 | 1 | 0 | 1 | 0 |
| Was allocation to treatment groups concealed? | 0 | 0 | 0 | 1 | 0 | 0 |
| Were treatment groups similar at the baseline? | 1 | 1 | 1 | 1 | 1 | 1 |
| Were participants blind to treatment assignment? | 1 | 0 | 0 | 0 | 0 | 0 |
| Were those delivering treatment blind to treatment assignment? | 0 | 0 | 0 | 0 | 0 | 0 |
| Were outcomes assessors blind to treatment assignment? | 1 | 1 | 1 | 1 | 1 | 1 |
| Were treatment groups treated identically other than the intervention of interest? | 1 | 1 | 1 | 1 | 1 | 1 |
| Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed? | 1 | 1 | 0 | 1 | 1 | 1 |
| Were participants analyzed in the groups to which they were randomized? | 0 | 1 | 0 | 1 | 1 | 1 |
| Were outcomes measured in the same way for treatment groups? | 1 | 1 | 1 | 1 | 1 | 1 |
| Were outcomes measured in a reliable way? | 1 | 1 | 1 | 0 | 0 | 0 |
| Was appropriate statistical analysis used? | 0 | 0 | 0 | 1 | 0 | 0 |
| Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial? | 1 | 1 | 1 | 1 | 1 | 1 |
| Total | 8 | 9 | 7 | 9 | 8 | 7 |