Title:

‘Mind the gap’ - A scoping review of long term, physical, self-management in Parkinson’s.

Word Count: 3386

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Abstract/ Structured summary

Background: Parkinson’s is a common progressive neurological condition characterised by impairments of movement and balance; and non-motor deficits. It is now accepted that physical activity is a fundamental for people with Parkinson’s (PwP), despite this PwP remain inactive. There is a social and financial drive to increase physical activity for PwP through physical self-management, however little is known about this concept.

Objective: This scoping review provides an overview of the literature concerning physical self-management for PwP and its provision, participation and uptake by PwP.

Design and sources of evidence: Systematic search of the databases; Medline, EMBASE, HMIC, CDSR, Cochrane Methods Studies, DARE, CINAHL, PEDro, PsycINFO and Cochrane Library using the search terms ‘Parkinson*’ and ‘self-manag*’ was undertaken alongside citation and grey literature searching and a consultation exercise.

Charting methods: A narrative summary was undertaken to describe the current state of the literature.

Results: 1959 studies were identified with nineteen papers from seventeen studies meeting the inclusion criteria - Three reviews, four experimental studies, three pre-post-test designs, six cross-sectional designs, one qualitative interview design and two mixed method designs.

Conclusion: The findings of this scoping review suggest a need for clarity on what ‘physical self-management’ means and involves, with a gap between what the evidence promotes and what is being achieved by PwP. Further research should focus on the amount, type, intensity and duration of physical self-management models including behavioural change approaches and how, where and by whom this should be implemented.

Word count: 241

Contributions of the Paper:

- Physical activity is an essential component of management for PwP but this review suggests there is a lack of clarity over what ‘Physical self-management’ means, looks like or how it should be delivered for PwP.
- Further research is needed to investigate ‘Physical self-management’ including the use of behavioural change models as well as physical models of care.

Key words: Parkinson’s, Physical, Self-management

Introduction

Parkinson's is a common progressive neurological condition characterised by impairments of movement and balance; and non-motor deficits [1]. It is estimated that caring for people with Parkinson's (PwP) in England costs the NHS in excess of £212 million a year [2]. It is now accepted that rehabilitation and exercise are fundamental components of management for PwP [3], alongside medical and surgical care. Participation in exercise programmes has been associated with improved quality of life, better walking ability, balance, strength, flexibility, cardiovascular fitness and a reduction in falls for PwP [3,4,5]. More globally, self-management, including physical and social rehabilitation programmes with integrated strategies for daily living, make a significant improvement in health-related quality of life with long term effect of disease severity [6]. Preventing a cycle of inactivity and engagement in regular long-term socially supported activity on a regular basis is a priority for PwP in the self-management of their condition.

In the UK, National Institute for Health and Care Excellence guidelines for Parkinson's [7] recommend all PwP have 'access to education and advice about physical activity'. This is supported by the charity Parkinson's UK stating their research priorities include; 'improving life' and 'taking control', with a current national initiative to design an exercise framework for self-management of activity [8]. There is a widely accepted view that PwP should be highly active with strong evidence to support its effectiveness [9], clinically Physiotherapists are well-positioned to address this issue. However, the current healthcare climate in the UK is not able to support sustained, high intensity input and therefore promotes the adoption of self-management principles through health policy to achieve this [10]. Governmental care and charitable policies for long term conditions emerge from the Chronic Care model [11], and the Health Foundation [10]. Respectively, both state specific components are required for effective self-management: partnership decision making and care planning; education and motivation in self-management using targeted approaches and structured information and; and, support to help people with social, emotional and physical impacts of their condition

The terms, exercise, physical activity and physical self-management are used interchangeably in the literature with reference to Physiotherapy. The European Guidelines for Physiotherapy for People with Parkinson's [9], details the role of Physiotherapy in providing exercise advise in the form of an evidenced based, bespoke therapeutic programme of exercises specific for managing the symptoms of the condition. This is often delivered in a health setting over short periods of time. In contrast, the Parkinson's UK Excellence Network promotes the use of socially delivered, community physical activities and classes in an effort to increase physical activity [8]. Indeed, self-management practice occurs within the social environment [12] and it is suggested that a number of nuanced factors are involved in the success or failure of its practice [13].

Rationale for the review:

Despite, robust evidence for the benefits [9] and ever increasing drive to promote physical self-management in Parkinson's [10, 11] only 28% of PwP in the UK reportedly gain support to be independently physically active [14], with an inconsistent approach and failings in opportunity and access [15]. It is currently unclear why this figure is not higher and despite the advice and evidence available PwP are not participating in exercise independently. The

role of physiotherapy in facilitating both exercise prescription in the health setting and increased physical activity in the social setting, both drivers towards independent, physical self-management of the condition is well evidenced. This in turn can lead to the adoption of independent exercise and physical activity in the form of physical self-management. The final stage of independence being cyclical concept as people continually seek new opportunities and development for their physical self-management needs. Physiotherapy is well positioned to facilitate at every stage of this pathway (Figure 1) alongside other exercise professionals within a multi-disciplinary team. In this respect it is our responsibility to better understand the 'gap' between 'what is being promoted' and 'what is being achieved' when delivering independent physical self-management for PwP.

*** Insert Figure 1 – Conceptual diagram of the components of physical self-management and the role of Physiotherapy.*

The rigorous and transparent method of a scoping review is ideally suited to map current areas of research in this field [16]. Using a descriptive, analytical approach enables consideration of all aspects of physical self-management to be considered [17].

Aim of the review

In line with the PRISMA guidelines for scoping reviews [18] this review aims to provide an overview of the literature concerning the apparent 'gap' between the robust evidence base to promote long-term physical activity for PwP and its provision, participation and uptake through physical self-management models.

The specific research questions posed seek to identify and map what is known from the existing literature about physical self-management in Parkinson's including:

a) Recommended models of physical self-management for PwP;
b) The level currently being achieved by PwP;
c) Factors that influence the uptake of physical self-management models in PwP?

Method

The method for this review was based on the framework outlined by Arksey and O'Malley [16], and the Joanna Briggs Institute guidance on scoping reviews [17] and follows all recommendations from the PRISMA – ScR guidelines [18] for the reporting of scoping reviews.

The following five phases were completed:

1. Identifying the research question

To address the stated aim, an explorative and broad research questions with specific components were posed.

2. Identifying relevant studies

In order to ensure a comprehensive search of the literature, the following databases were searched for articles: Medline, EMBASE, HMIC, CDSR, Cochrane Methods Studies, DARE, CINAHL.,PEDro, PsycINFO and CochraneLibrary. The search strategy was constructed using a mixture of MeSH and free text words. The search terms 'Parkinson*' and 'self-manag*' were combined with the boolan operator 'AND' up to 22nd February 2018, within the selection of 'English language'. A final search strategy for MEDLINE can be found in Additional file 1. Reference lists of included studies were also scanned for relevant articles and citation chasing of included papers. Published material from relevant organisations for citations of interest, such as the charities Parkinson's UK and MJ Fox Foundation and the Association of Physiotherapists Interested in Neurology, Association of Physiotherapists in Parkinson's Disease Europe and the Chartered Society of Physiotherapy were also searched. In addition to literature searching a Consultation exercise is also recommended as part of an exhaustive scoping review strategy [16]. Therefore, a convenience sample of Health professionals and physical activity providers for PwP were also asked for recommendations of literature. This included one Parkinson's nurse consultant, two neurological physiotherapists, one yoga teacher and two dance teachers all specialising in Parkinson's. Professionals were invited to contribute based on the frequency of work with PwP and their involvement with activities within the physical management domain.

3. Study selection

Once identified through all search methods all relevant literature was screened by title and abstract by the lead author. Papers were included if they reported:

- An intervention aimed at changing self-management of physical activity in Parkinson's;
- Recommended physical activity levels for PwP;
- Current physical activity levels of PwP;
- Experiences, adherence, attitudes and barriers to self-management of physical activity by PwP.

Full text copies of literature meeting this criteria were read by the lead author and checked by a second reviewer (VG), with any discrepancies being discussed against the inclusion criteria and research question.

As this is a scoping review, no formal assessment of methodological quality was performed, rather focusing on gathering a broad understanding of the field and identifying all relevant literature regardless of design.

4. Charting the data

A descriptive analytical approach was taken to chart the data. Key information was extracted including in the following headings: Author, Date and Country; Literature content in relation to research question sub themes: a) Recommended Physical self-management models in PwP, b) The level being achieved by PwP, c) Factors that influence the uptake of physical self-management by PwP; Study design; Population; Intervention; Main outcome.

Initial extraction took place by the lead reviewer (SH), this was cross checked by the second reviewer (VG) for all included papers.

5. Collating, summarising and reporting the results.

Data were collated and summarised for each study in Table 1. The results of the summary are discussed as they relate to the aim of the review and each objective with limitations and recommendations to future research direction.

Results

Results are presented based on the methodological framework for scoping reviews [16]. Figure 2 represents the search results from each stage of the review process. A total of 1959 studies were identified with nineteen papers from seventeen studies meeting the inclusion criteria (Table 1). No additional studies were identified in the consultation exercise although clinical guidelines referred to are included in the discussion of this review.

Three of the studies identified were review papers (Table 1), although only one of these could be classed as a systematic review with the others being narrative (non-systematic) reviews. Fereshtehnejad and Lokk [19] suggested self-care must include self-maintenance, self-monitoring and self-management as part of an active ageing model and that this can be achieved through patient education and the use of technology. Hirsch [20] proposed a model where caregivers and peers are trained to deliver community exercise programmes. A systematic review of eighteen qualitative or quantitative studies [21] reported heterogeneous interventions in terms of delivery and content, with limited descriptions of the components of self-management programmes although those that did report related to education, goal setting and problem solving. No consensus was reached in terms of the best model for physical self-management in Parkinson's and all highlighted the need for further research in novel and multifactorial models of physical self-management for PwP with multi-dimensional evaluation design.

Seven experimental studies examining models of physical self-management were included (Table 1) of which four were randomised controlled trials (RCT) [6, 22-24] and three used a single arm, pre-post study design [25-27]. Five were reported as full-text papers with two only available as an abstract (including a PhD thesis). Many of the programmes included exercise as well as a self-management programme or strategies, however the level of detail regarding the self-management aspects of the intervention was often limited and didn't conform to TIDieR guidelines [28]. A broad range of outcome data were collected relating to impairments, activities, personal factors and quality of life.

Six studies used a cross-sectional design to establish physical activity levels or factors associated with exercise (Table 1) [29-34]. Reports of physical activity levels varied across those four studies looking at this outcome as did the factors associated with physical activity [31-34].

Collectively there were fewer qualitative studies identified. One study used semi-structured interviews and a grounded theory approach to investigate the meaning of exercise and sustained self-management in the form of participation in group exercise [35]. Ramaswamy [36] utilised Participatory Action Research to explore role of physiotherapy for PwP undertaking activities to attain wellness and as a result developed a socially-driven consensus model of self-management, facilitated by physiotherapists, to empower PwP to self-manage. Focus groups investigating opinions of exercise with people with progressive neurological disorders, including PwP, reported that disease specific considerations and

confidence in health professionals were important factors, along with the perception and enjoyment of exercise [37].

Discussion:

The research question sought to identify what is known from the existing literature about physical, self-management in PwP in order to identify gaps in the evidence base and the delivery. In accordance with the criteria of a scoping review the inclusion and exclusion criteria were deliberately broad [17] with a total of nineteen studies meeting the inclusion criteria.

Overall, despite clinical, policy and institutional drive towards the promotion of physical self-management [7-11], results of this review suggest that the concept itself is not referred to in the literature with findings varied and limited in their descriptions. No literature directly referred to the term 'physical self-management', rather descriptions of socially driven exercise and activity models, where the responsibility to participate was shared between the stated activity provider and the patient. In comparison, literature is available to discuss the self-management of medications and disease monitoring [38] with the use of technology to achieve this being widely discussed [39]. This poses the questions – where did the concept of 'physical self-management' derive from and do current clinical models of care acknowledge the need and benefit of personal, physical self-management models for PwP? The results of this review suggest the concept is unclear at present.

In an effort to unpack the concept of 'physical self-management', the pre-stated research question further identified three main topics that were important in understanding the state of literature in the field; a)Recommended models of physical self-management for PwP; b) The level currently being achieved by PwP; c) Factors that influence the uptake of physical self-management models in PwP.

A) Recommended models of physical self-management for PwP

Fifteen studies made reference to exercise and physical activity which has been interpreted here as physical self-management model. All discuss a positive outcome for a combined physical and educational model, but no consensus was reached on the best mode, intensity or duration of interventions. Studies were predominantly small in sample and most lacked a standardised control. In addition, no study followed the recommended TiDER guidelines for intervention reporting [28] and as such no details are available on what the content, delivery location (ie social or health care setting) or practitioners involved should be.

When addressing self-management, the importance of supported behavioural change to sustain new health behaviours is clear as without it transition from health care provision to true self-management is unlikely or at best vulnerable [30]. An added consideration is the continually changing presentation of Parkinson's, presenting new physical and psychosocial challenges, coupled with the known effects of disease specific apathy and depression [1]. Both these considerations increase the need for supported behaviour change models specific to the condition if activity is to be instigated and maintained at a clinically meaningful level. Three [24, 26, 31] studies specifically address this, concluding individual behaviour change supported by social and organisational change provides the most promise for developing effective community based physical self-management models [26]. However, no studies provided detail of how this was or should be implemented. Clinically, both the

European Guidelines for Physiotherapy for Parkinson's [9] and the Parkinson's UK, Exercise framework [8], explicitly suggest what type of activities PwP should take part in as 'Physical self-management' but again no reference is made to a combined physical (exercise and activity) and psychosocial (behavioural management) approach or how to encourage or achieve it. This presents a conflicting picture, in that research studies appear to suggest the importance of a combined model with limited evidence findings and descriptions, but the promotion of best practice though clinical and patient focused guidelines do not endorse or facilitate this. Perhaps a shift in focus is needed towards health professionals becoming involved in behaviour change at the social level in order to achieve optimum health benefits, rather than focusing solely on activities for specific impairments or symptom management?

B) The level of physical self-management currently being achieved by PwP:

Of the 19 studies, only three made specific reference to the current levels of physical self-management achieved by PwP [31-34]. As clinically relevant improvement rates for rehabilitation have been anticipated between 25-53% greater than medication alone [6] the importance of PwP taking part in physical exercise is undisputed. Despite this, only 51.9% of PwP reach the recommended level of exercise (30 minutes 5 x per week) [40] and 80% of PwP correctly identify themselves as being inactive [30]. If we are to promote the rehabilitative potential of exercise and physical activity, there is a clear need for specific guidelines for PwP on the recommended levels of exercise to achieve the desired gains as well as education and support on how to instigate and maintain these levels. Evidence suggests, simply promoting the benefits and suggesting potential models of participation are not providing the necessary resources to instil behaviour change.

C) Factors that influence the uptake of physical self-management models in PwP.

Studies predominantly discuss the reported barriers to maintaining physical activity within a socially driven model including the specific importance of peer support [20, 26, 36] and social networks as well as confidence in the trainers [37] and availability of ongoing support [19]. External factors were also identified such as access, cost and transport [23,32,37] as well as personal factors such as patient level of education [31] and gender (females less likely to engage)[33], all of which reflect the multi-dimensional considerations for physical self-management. Throughout all literature [30-32,35,36], the strongest influencing factor identified was a person's self-efficacy. Whether discussed through qualitative enquiry or standardised outcome measures, self-efficacy consistently showed a direct influence on uptake and adherence of physical self-management in PwP [31]. All these factors point towards a need for bespoke, disease specific models in the social setting and not the health delivered, individualised treatment model currently, predominantly provided in the health service [16]. In support of this, social drivers were cited as being more influential than physical impairment [20,30,31], although symptoms and impairments were reported as influential factors [30,31,33], which again points towards a socially driven, multi-dimensional (physical and behavioural change) model delivered in the community.

Overall, this review suggests that 'Physical self-management' is a combination of factors and not just the delivery of exercises or activity prescription from a physiotherapist or other exercise professionals within the multi-disciplinary team. It is possible, that the broad search terms of 'Parkinson's' and 'Self-management' used failed to identify articles related to the specific aspects identified such as behavioural change, socially driven models and exercise

behaviours, particularly due to the mis-conceptions of the term ‘physical self-management’. In contrast the large number of studies found relating to general self-management of Parkinson’s or medication and disease modification measures suggests the physical aspects of self-management are under researched. Guidance can be sought from ‘physical self-management’ models adopted in other conditions such as the ‘Move more’ guide to becoming more active following cancer which has both a patient workbook including physical and psychosocial guidance alongside evidenced based recommendations for facilitators [41], or the ‘Bridges self-management model for life after Stroke’ or ‘long term conditions’ [42]. From a generic aspect, the ‘Kings Fund - Self-management for Long-term Conditions-Patients perspectives on the way ahead’ [43] provides advice on how health and social care providers can support patients in line with their individual needs.

Future research should focus on better understanding the concept of ‘physical self-management’ from the perspectives of patients, clinicians and policy makers to enable clear and effective collaboration. Exploration of how this could be implemented with acknowledgment of the need for a better understanding of the physical model (frequency, intensity, time and type of activity) and the psychosocial model in relation to behavioural change is also needed. Finally, clinical research to show the potential holistic and biopsychosocial long-term effect of physical self-management for PwP and cost-effectiveness needs to be undertaken.

Conclusion

This review has enabled a greater understanding of the available literature regarding physical-self management in PwP. Specifically, the three focused areas demonstrate that whilst widely discussed and promoted in the clinical setting, policy and guidelines physical self-management is mis-understood and under researched from an evidence base. Questions regarding the concept, content, most appropriate location and facilitators remain unanswered as well as the combination of physical activity and behavioural change models to gain the necessary clinical effectiveness (Objective A). Despite a strong evidence to support physical activity for PwP there is a lack of evidence on what is and should be achieved (Objective b) and it appears self-efficacy is a major influencing determinant to the achievement of ‘physical self-management (Objective C).

Further research is needed to ‘bridge the gap’ between the evidence for physical activity and exercise in PwP and actual levels of participation. In the current healthcare climate with limited resources, Physiotherapy and associated exercise professionals are ideally suited to facilitate this transition and help PwP start to realise the health and social benefits that are so widely promoted when adopting a physical self-management approach.

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Conflict of interest: None declared.

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Additional file 1

Example of search strategy used. Performed by lead author S. Hulbert and checked by V. Goodwin.

MEDLINE search strategy (literature search performed on 22nd February 2018):

(Parkinson*[tiab] OR Parkinson[mesh]) AND (Self*[tiab] OR management*[tiab]OR self-management[mesh])

1. Parkinson*

2. Self manag*

3. Combined with AND

4. Filter ‘English language’