Fear-of-falling activity-avoidance behavior in people with Parkinson’s disease: a scoping review protocol

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ABSTRACT

Objective: The objective of this review is to explore existing literature related to fear of falling activity avoidance behavior and identify what is known about this phenomenon in people with Parkinson’s disease.

Introduction: Falling and fear of falling are significant concerns for persons with Parkinson’s disease. Fear of falling is a significant problem over and above falling itself and can lead to activity avoidance. Activity-avoidance behavior is a risk factor for increased falls and can lead to further functional decline. A better understanding of the fear of falling and the associated avoidance behavior can inform screening, evaluation, and interventions to decrease fall risk and improve activity engagement and quality of life for persons with Parkinson’s disease.

Inclusion criteria: This review will consider studies published in English that include individuals diagnosed with Parkinson’s disease experiencing fear of falling that impacts activity engagement with no limit on participant age or time of publication.

Methods: JBI methodology will be used to conduct this scoping review. A three-step search strategy will be utilized. The databases to be searched include MEDLINE (PubMed), Embase (Elsevier), Scopus (Elsevier), APA PsycINFO (EBSCO), CINAHL (EBSCO), Papers First (OCLC), and ProQuest Dissertations and Theses (ProQuest). Two independent reviewers will screen the titles, abstracts, and full text of the selected studies. Data collection will be performed with a tool developed by the researchers based on the standardized tool from JBI SUMARI. Data will be presented in a comprehensive narrative summary.

Keywords: activity avoidance behavior; fall prevention; fear of falling; Parkinson’s disease; scoping review


Introduction

Parkinson’s disease (PD) is the second-most-common neurodegenerative disorder of aging and the most common movement disorder.1 Parkinson’s disease is a progressive neurodegenerative disorder in which individuals lose cells in the substantia nigra and have significantly decreased dopamine concentrations in the striatum.2 Clinical features of PD are often grouped under the acronym TRAP: Tremor at rest, Rigidity, Akinesia, and Postural instability.2 In addition to these cardinal features, freezing of gait, flexed posture, and many non-motor symptoms, such as autonomic dysfunction, cognitive and neurobehavioral disorders, sensory changes, and sleep abnormalities are also commonly observed.2 In clinical practice, diagnosis is based on the presence of a combination of typical motor features, associated and exclusionary symptoms, and response to Levodopa.3 Falling is a significant concern for persons with PD,4 with 60.5% of individuals reporting at least one fall each year, and approximately 39% reporting multiple falls each year.5 Recurrent falling substantially increases the likelihood of injury and long-term disability.6 Factors contributing to falls are typically characterized as either extrinsic (outside the individual, such as the environment) or intrinsic (arising from within the individual, such as impaired cognition or emotional status).7 One of the intrinsic variables associated with falling is fear of falling.8–10

Fear of falling may develop as a direct consequence of a fall; however, it may also surface without any history of falls.11 For many individuals with PD, fear of falling is experienced daily.4 In an attempt to
decrease the fear and anxiety around falling, persons with PD may begin to avoid activities that they perceive as putting them at risk for a fall. Up to three-quarters of all adults 65 years and older avoid at least one daily activity due to fear of falling, with 15% reporting severe activity restrictions. It has been reported that individuals with PD have a greater fear of falling than similarly aged healthy adults. Some degree of fear of falling may be considered protective and beneficial, especially in those with poor balance and at high risk for falls. However, when activity avoidance is not balanced with functional abilities, it can lead to sedentary behavior and social isolation, eventually leading to deconditioning and further functional decline.

Fear, anxiety, and/or catastrophizing about future falling have all been shown to contribute to the avoidance behavior, leading to an increased need for assistance with daily activities, which has been described as a leading cause of disability in the elderly. Fear of falling is characterized by high levels of anxiety related to walking or engaging in an activity with the fear that it might cause a fall. Fear of falling was first recognized as an internal phenomenon or anxiety, often, but not always associated with actual falling, with significant impact on purposeful activity and independence, that may lead to deconditioning and functional loss.

Other terms commonly associated with fear of falling are “balance confidence” (an individual’s confidence in performing various activities without falling) or “falls efficacy” (operationalizing fear of falling as low perceived self-efficacy at avoiding falls during essential, nonhazardous activities of daily living); both terms will be included in the search strategy. Although limited evidence exists for optimal treatment of fear-of-falling activity-avoidance behavior, recommendations are to address it early in order to prevent sedentary behavior and further participation restrictions. In current literature, fear of falling and activity avoidance behavior are commonly assessed using self-reported psychological-based measures, such as the Falls Efficacy Scale (FES), Activities-specific Balance Confidence scale (ABC), and the Fear of Falling Avoidance Behavior Questionnaire (FFABQ).

Activity avoidance behavior can be described as a restriction of one’s activities, any form of avoidance of activities, or foregoing participation in any daily activity. For the purposes of this review, activity avoidance is viewed as a result of a fear of falling. Participants actively avoiding activities may or may not have valid balance concerns and may be avoiding activities that do or do not have an increased fall risk. The adoption of sedentary and isolated lifestyles of activity avoidance behavior from increased fear and anxiety often leads to functional decline and even institutionalization. Avoidance behavior has been shown to be a risk factor for further falls.

A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews, and the JBI Database of Systematic Reviews and Implementation Reports was conducted and no current or in-progress systematic or scoping reviews on fear-of-falling activity-avoidance behavior among people with PD were identified. The objective of this scoping review is to explore existing literature related to fear-of-falling activity-avoidance behavior, assessments used to gather this information, and interventions used to treat this phenomenon among people with PD.

Review questions

i) What literature exists on fear-of-falling activity-avoidance behavior in people with PD (specifically, the behavioral impact of fear of falling on activity selection and engagement in people with PD)?

ii) What assessments are used to measure fear of falling and its impact on daily activities among people with PD?

iii) What interventions are being used to address fear-of-falling activity-avoidance behavior among people with PD?

Inclusion criteria

Participants

The review will consider studies that include adults 18 years and older diagnosed with PD experiencing fear-of-falling activity-avoidance behavior. Studies with mixed populations will be considered for inclusion if data can be extracted specific to PD. For the purposes of this scoping review, PD will be categorized as a physician diagnosis based on the current clinical practices (eg, presence of the cardinal motor and non-motor features, associated and exclusionary symptoms, and response to Levodopa).
Concept
The concept to be studied in this review is fear-of-falling activity-avoidance behavior. This review will seek to identify what literature exists on fear-of-falling activity-avoidance behavior among people with PD and how the fear of falling experienced by those with PD may influence activity selection and engagement. Although multiple fear-of-falling assessments exist, they do not all capture the concept of activity avoidance in consequence to the fear of falling. Studies will be excluded if they only address fear of falling without discussing the behavioral impact of activity avoidance. This review will also seek to better understand what assessments can be used to identify the effect, if any, of fear of falling on activity-avoidance behavior. Additionally, this review will seek to better understand what interventions are being used to mitigate fear-of-falling avoidance behavior, as well as what factors of fear-of-falling activity-avoidance the identified interventions were designed to address.

Context
This review will consider studies that are conducted in any context (eg, hospitals, outpatient and inpatient rehabilitation settings, home and community) or geographical location.

Types of sources
This scoping review will consider both experimental and quasi-experimental study designs, including randomized controlled trials, non-randomized controlled trials, before and after studies, and interrupted time-series studies. In addition, analytical observational studies, including prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies will be considered for inclusion. This review will also consider descriptive observational study designs, including case series, individual case reports, and descriptive cross-sectional studies for inclusion.

Qualitative studies that focus on qualitative data, including, but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description, and action research will also be considered. Text and opinion papers will also be considered for inclusion in this scoping review.

Published and unpublished studies in English will be included. This review will consider all relevant studies with no limit on the dates of publication.

Methods
The proposed scoping review will be conducted in accordance with JBI methodology for scoping reviews. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) will also be followed.

Search strategy
An initial limited search of MEDLINE (PubMed), and CINAHL (EBSCO) was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy for PubMed (see Appendix I). The search strategy, including all identified keywords and index terms, will be adapted for each included information source. The reference list of all studies selected for inclusion will be screened for additional studies.

The databases to be searched include MEDLINE (PubMed), Embase (Elsevier), Scopus (Elsevier), APA PsycINFO (EBSCO), and CINAHL (EBSCO). Sources of unpublished studies and gray literature to be searched include Papers First (OCLC) and ProQuest Dissertations and Theses (ProQuest).

Study selection
Following the search, all identified citations will be collated and uploaded into RefWorks (Legacy Version; ProQuest LLC, Ann Arbor, USA) and duplicates removed. Titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant studies will be retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia). The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of full-text studies that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the study-selection process will be resolved through discussion or with a third reviewer. The results of the search will be reported in full in the final scoping review and presented in a PRISMA flow diagram.
Data extraction

Data will be extracted from papers included in the scoping review by two independent reviewers using a data extraction tool developed by the reviewers based on the standardized tool from JBI SUMARI.27 The data extracted will include specific details about the population, concept, context, study methods, and key findings relevant to the review objective. A draft charting table is provided (see Appendix II). Modification of the JBI data extraction tool consists of the addition of the following items: details about measurements/assessments used for fear-of-falling activity-avoidance behavior, and details about intervention methods used to address fear-of-falling activity-avoidance behavior. The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included study. Modifications will be detailed in the full scoping review report. Authors of papers will be contacted to request missing or additional data, where required.

Data analysis and presentation

The extracted data will be presented in diagrammatic or tabular form in a manner that aligns with the objective of this scoping review. A narrative summary will accompany the tabulated and/or charted results and will describe how the results relate to the scoping review’s objective and questions.

Acknowledgments

Jason Fetty, MLIS, AHIP, for assistance in the development of search strategies of database systems.

References

Appendix I: Search strategy

MEDLINE (PubMed)
Search conducted on January 8, 2020.

### Appendix II: Data extraction instrument

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