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Hannah Trotman, Dikaios Sakellariou, Fiona Wood & Katy Hamana

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Mapping social participation interventions for adults with a neurodegenerative condition: a scoping review of in-person and digital community approaches

Hannah Trotman[a], Dikaios Sakellariou[a*], Fiona Wood[b] and Katy Hamana[a]

[a]School of Healthcare Sciences, Cardiff University, Cardiff, UK; [b]School of Medicine and PRIME Centre Wales, Cardiff University, Cardiff, UK

ABSTRACT

Purpose: Individuals with neurodegenerative conditions, such as Parkinson's, Huntington's, Dementia, and Multiple Sclerosis, often experience significant social isolation due to physical and cognitive limitations that hinder social participation. Social isolation can lead to loneliness and reduced quality of life. This scoping review aimed to map interventions designed to enhance social connectedness and mitigate these effects.

Methods: Following Arksey and O'Malley's scoping review framework, key databases were searched. Inclusion criteria focused on interventions fostering social participation in adults with neurodegenerative conditions. Themes were identified through a narrative synthesis approach.

Results: A total of 1,038 articles were screened, with 37 meeting the inclusion criteria. Most interventions involved in-person group activities, with digital interventions representing a smaller area. The synthesis revealed three themes: intervention details, theoretical frameworks, and evaluations. These themes highlighted key components and theoretical foundations that informed interventions but also identified implementation challenges with accessibility and inclusivity for individuals with varied needs.

Conclusions: The findings underscore the need for diverse, accessible interventions to foster social connectedness for individuals with neurodegenerative conditions. Future research should focus on refining intervention design to improve inclusivity, addressing barriers to enhance participation in both in-person and digital formats.

IMPLICATIONS FOR REHABILITATION

- Neurodegenerative conditions increase social isolation, highlighting the need for targeted interventions to enhance quality of life.
- In-person interventions support social participation but must be adaptable for diverse needs.
- Digital options offer accessible ways to maintain social ties for those with limited mobility.
- Rehabilitation should focus on scalable, inclusive interventions that overcome participation barriers across disease stages.

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Neurodegenerative conditions; neurological conditions; social participation; digital interventions; scoping review; community engagement; loneliness; isolation

Introduction

Background and rationale

Social participation, defined in the International Classification of Functioning, Disability and Health (ICF) [1] as "involvement in a life situation" especially in relation to community, social and civic life, is a seemingly critical aspect of daily living. Despite this, there is a lack of comprehensive understanding and consolidation of interventions that effectively promote social participation, notably for individuals with neurodegenerative conditions. People living with such conditions often experience barriers to participation, not only due to physical and cognitive impairments, but also because of stigma [2], which can result in social withdrawal and diminished access to community resources [3]. Existing literature suggests that interventions targeting social participation can have significant positive outcomes [4], including improved mood [5], enhanced cognitive function [6], and better overall quality of life [7], as well as reduced loneliness [8], improved self-efficacy [9], and greater independence [10]. However, these studies have been found to be often fragmented, with varying methodologies and outcomes. Moreover, whilst digital technologies have shown promise in bridging the gap for those who are physically isolated or have mobility issues [11], they are not well documented in the context of neurodegenerative diseases. As such, whilst telehealth services, online support communities, and mobile applications offer innovative ways to engage individuals in social activities, their adoption and effectiveness are yet to be conclusively synthesised in relation to their ability to improve social connectedness in this population.

A comprehensive review of interventions targeting social participation may highlight gaps in the current research, offering directions for future studies. Identifying these gaps is essential for developing targeted strategies and informing policy decisions

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CONTACT Hannah Trotman TrotmanH@Cardiff.ac.uk School of Healthcare Sciences, Cardiff University, Cardiff, UK
*Present address: Department of Health Sciences, European University Cyprus, Nicosia, Cyprus.
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that can enhance support systems for individuals with neurodegenerative conditions.

This review therefore aims to identify the types of activities and digital interventions that have been reported in the literature and highlight any gaps in the current research landscape. Thus, we will provide a comprehensive overview of the existing evidence base to inform future research, policy, and practice. As such, the primary aim of this scoping review is to synthesise the scope of initiatives promoting social participation and connectedness for adults with neurodegenerative conditions. A secondary aim of this review is to explore the use and acceptance of digital technologies designed to reduce loneliness and promote social connectedness in individuals with neurodegenerative conditions. By doing so, this review will offer valuable insights into effective strategies, identify research gaps, and support the development of interventions aimed at improving the quality of life for this vulnerable population.

Method

Protocol

This scoping review was conducted in accordance with a published protocol [12] to ensure methodological rigour and transparency throughout the review process. The protocol was developed following the Arksey and O'Malley framework for scoping reviews (Supplemental Materials 1) [13] and the guidelines of the "Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews" (PRISMA-ScR) [14].

Review questions

In line with the objectives of this scoping review, the primary question is structured according to the Population, Concept, Context (PCC) framework as follows [15]:

> *"What types of activities (Concept) are available and have been documented to support participation and social connectedness (Concept) for adults (Population) living with neurodegenerative conditions (Population) within community settings (Context)?"*

This primary question addresses the core aim of the review by focusing on the variety and characteristics of interventions designed to enhance social participation and reduce isolation among individuals with neurodegenerative conditions. This includes both formal interventions led by healthcare professionals or trained facilitators and informal activities organised within community settings. By examining the breadth of these interventions, the review aims to provide a comprehensive understanding of the current landscape and identify successful strategies that could be scaled or adapted for broader use.

To address the secondary aim of the review, the following sub-question will be explored:

> *"Are digital technologies (Concept) being utilised for these activities to enhance participation and reduce loneliness for adults with neurodegenerative conditions (Population) in various settings (Context)?"*

This question aims to assess the range and scope of digital interventions, providing insights into how technology is being leveraged to address the social needs of this population. Digital technologies can overcome geographical barriers and offer flexible options for engagement, making them particularly valuable for individuals with mobility issues or those living in rural or underserved areas. The review aims to examine interventions adopting various digital platforms, their usage, user satisfaction, and reported outcomes. Understanding the facilitators and barriers to the adoption of these technologies will also be a key focus, including examining factors such as accessibility for effective implementation. Insights gained from this analysis will highlight the accessibility and user-friendly nature of these digital interventions.

Search strategy

A comprehensive search strategy was employed to capture a wide range of relevant studies. The databases searched included MEDLINE (*via* OVID), SCOPUS, CINAHL (*via* EBSCO), PsycINFO (*via* OVID), and ProQuest. These databases were selected for their extensive coverage of biomedical, health, and social science literature. Searches were also conducted *via* ProQuest Dissertations and Theses Global to capture grey literature not available in academic journals. The final database search was conducted on 7th May 2024.

A two-step search strategy was utilised, comprising of an initial search, and then a refined strategy, locating both published and unpublished work. The general search strategy details used for each database search is outlined in Appendix A. Initial searches on MEDLINE and SCOPUS utilised the keywords "exercise," "social participation," "neurological conditions," "Parkinson's," "Huntington's," "Multiple Sclerosis," "Alzheimer's," "Motor Neuron Disease," "community support," and "loneliness". The final comprehensive search strategy, underpinned by the initial keywords and refined with additional index terms, truncations and synonyms, was collaboratively developed with a subject librarian to ensure robustness of the search strategy (see Table 1).

Inclusion and exclusion criteria

The inclusion/exclusion criteria were structured around PCC framework [15].

Participants

Adults, living with neurodegenerative conditions, including, Huntington's, Parkinson's, Ataxia, Dystonia, Alzheimer's, Multiple Sclerosis, and Motor Neuron Disease. Healthcare professionals, volunteers and/or activity organisers working with individuals with

Table 1. Search strategy concept and search strings.

Concept	Search string
Condition	"Parkinson* Disease" OR "Huntington* Disease" OR "Multiple Sclerosis" OR "Motor Neuron? Disease" OR Ataxia OR Dystonia OR "Alzheimer* Disease" OR Neurological OR "Neurological Condition" OR "Neurological Disease" OR Neurodegenerative OR "Neurodegenerative condition" OR "Neurodegenerative Disease"
Participation	Leisure OR "Physical Activit*" OR "Activit* Of Daily Living" OR Participat* OR Interact* OR Talk* OR Engage* OR Connect* OR Recreation* OR "Social Participation" OR Lonely OR Loneliness OR Alone OR Connected* OR Isolated OR "Social Connection" OR "Social Interaction" OR "Social Isolation" OR "Social Network" OR "Social Engagement" OR Engagement OR "Social Wellbeing" OR "Psychosocial Wellbeing" OR Wellbeing OR Psychosocial
Intervention	Intervention* OR Program* OR Course* OR Group OR Class OR Community OR "Social Program*" OR "Social Group" OR Digital OR Remote OR EHealth OR Online OR Virtual OR Electronic OR Internet OR Telehealth

neurodegenerative diseases. Studies that focused on paediatric populations, or adults without diagnosed neurodegenerative conditions/activity organisers, were excluded.

Concept

The concept of interest was the range of activities designed to support participation and social connectedness, aimed specifically at reducing loneliness and isolation. As such, inclusion criteria for activities were defined to include, but were not limited to, physical activities, recreational programs, social gatherings, peer support groups, and the use of digital technologies as facilitators for such interactions.

Context

The context of this review encompassed community settings which was defined to include, but was not limited to, local community centres, sports clubs, social clubs, residential care, and supported living facilities. The review considered studies from any geographic location and was sensitive to cultural and sub-cultural factors that may have influenced the design, delivery, and outcomes of the activities. Studies that were based in hospital settings, inpatient rehabilitation, or other healthcare-specific environments were excluded.

Types of sources

- Experimental and quasi-experimental study designs
- Observational studies
- Descriptive studies
- Qualitative studies
- Additionally, grey literature (evidence published online but not in academic peer reviewed journals) and reviews that provided relevant insights into the review concepts were also included.

The scoping review included studies published in the English language. The temporal scope of the search was established from the year 2008 onwards. This starting point is significant as it coincides with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which was adopted in 2006, but entered into force in 2008 [16].

We acknowledge the ongoing debate surrounding the classification of some conditions, such as multiple sclerosis, often considered neuroinflammatory, and dystonia, which may also appear as a symptom of other disorders. However, these conditions were included in this review based on their classification within major clinical frameworks [17], their treatment as neurodegenerative or progressive neurological conditions within clinical settings [18], and their significant impact on individuals' ability to engage in social participation. We referred to definitions outlined by the World Health Organisation's International Classification of Diseases (ICD-11) [17], which categorises a range of neurodegenerative diseases under "Diseases of the Nervous System", including Alzheimer's, Parkinson's, Huntington's, multiple sclerosis, and Motor Neuron Diseases. Notably, ICD-11 also classifies primary dystonia as a neurological condition in its own right (code 8A02), rather than solely as a symptom [17], which supports its inclusion within the scope of this review. In addition, the Mayo Clinic's clinical resources were consulted to ensure practical alignment with conditions commonly treated as neurodegenerative within clinical settings [18]. Further reflection on these classification complexities is provided in the Discussion.

Study selection

The selection process followed a rigorous two-stage screening approach to ensure only relevant studies were included in the final review. Initially, all titles and abstracts identified through the database search were screened against predefined inclusion and exclusion criteria. Studies were included if they focused on interventions promoting social participation among individuals with neurodegenerative conditions and reported empirical data.

In the second stage, full-text screening was conducted for those studies that met the criteria in the first stage. The full-text articles were reviewed in detail to confirm their relevance and quality. As this screening process involved only one researcher, any discrepancies were discussed and resolved via meeting with the full review team. Studies were excluded if they lacked detailed descriptions of interventions, focused on unrelated populations, or were theoretical in nature. This careful selection process ensured the inclusion of studies that directly addressed the review's objectives and provided sufficient data for thematic synthesis.

Data extraction and synthesis

A thematic synthesis was employed in this review, guided by established methodological recommendations [19]. The initial coding of data was inductive, allowing themes to emerge from the content of the included studies. To support structured comparison and consistent reporting across interventions, the Template for Intervention Description and Replication (TIDieR) checklist [20] was introduced during the synthesis phase. This framework enabled the organisation of intervention details such as delivery mode, frequency, duration, tailoring, and theoretical underpinning. While the core thematic coding remained grounded in the data, TIDieR was used to inform the organisation and presentation of descriptive and analytical themes.

The data extraction tool for this scoping review (Appendix B) was adapted, based on the established Cochrane data extraction template [21]. The adapted template included fields specific to the research questions such as "type of neurodegenerative condition" and was piloted on a small subset of included studies to confirm its efficacy in capturing all necessary information. In accordance with scoping review methodology, an assessment of methodological quality of included articles was not performed [9].

Once data extraction was complete, the lead author conducted the initial coding of a subset of the included studies. To enhance the consistency and reliability of the coding framework, other members of the research team independently coded the same studies. Discrepancies were discussed and resolved, and the final coding framework was applied across the dataset. Descriptive themes were refined into broader analytical themes, which provided a deeper understanding of how various interventions were implemented and their overall effectiveness.

Results

Study selection and characteristics

Following the initial retrieval of 1038 articles across several databases, the consolidation process was undertaken using EndNote (Software version 20.7). Duplicates were removed using the EndNote duplicate remover software, which identified 616 articles. After the automated duplicate removal process, a hand search was conducted to ensure no duplicates were missed, which resulted in no further duplicates being identified. The first screening process involved reviewing the titles and resulted in the removal of 288 articles that were deemed irrelevant to the study objectives. The remaining 136 articles were then subjected to abstract screening. This process led to the exclusion of a further 91 articles and after full-text screening, a final count of 37 articles were deemed relevant for inclusion in this review. The full reasons for the removal of 9 articles after the full-text screening, along with complete citations, are displayed in Appendix C. The PRISMA flowchart [22] in Figure 1 details the study selection process.

Description of included articles

The included articles varied in design, country of origin, and sample size. Study designs encompassed qualitative, quantitative, and mixed-method approaches, with sample sizes ranging from small pilot articles to reports of large-scale interventions (see Table 2). Most studies were conducted in the regions of Europe, North America and Australasia, notably, only one study was conducted in the Middle East.

Types of neurodegenerative conditions

The articles reviewed encompassed a range of neurodegenerative conditions. Parkinson's disease was the most frequently studied condition, represented in 18 articles (46.16%). This was followed by Multiple Sclerosis which was studied in 17 articles (43.60%). Two articles studied both Parkinson's disease and Multiple Sclerosis, which explains the count of 39 conditions across 37 articles. Further, to maintain clarity and consistency, "Dementia" in this review is defined to include Alzheimer's Disease along with other forms of Dementia.

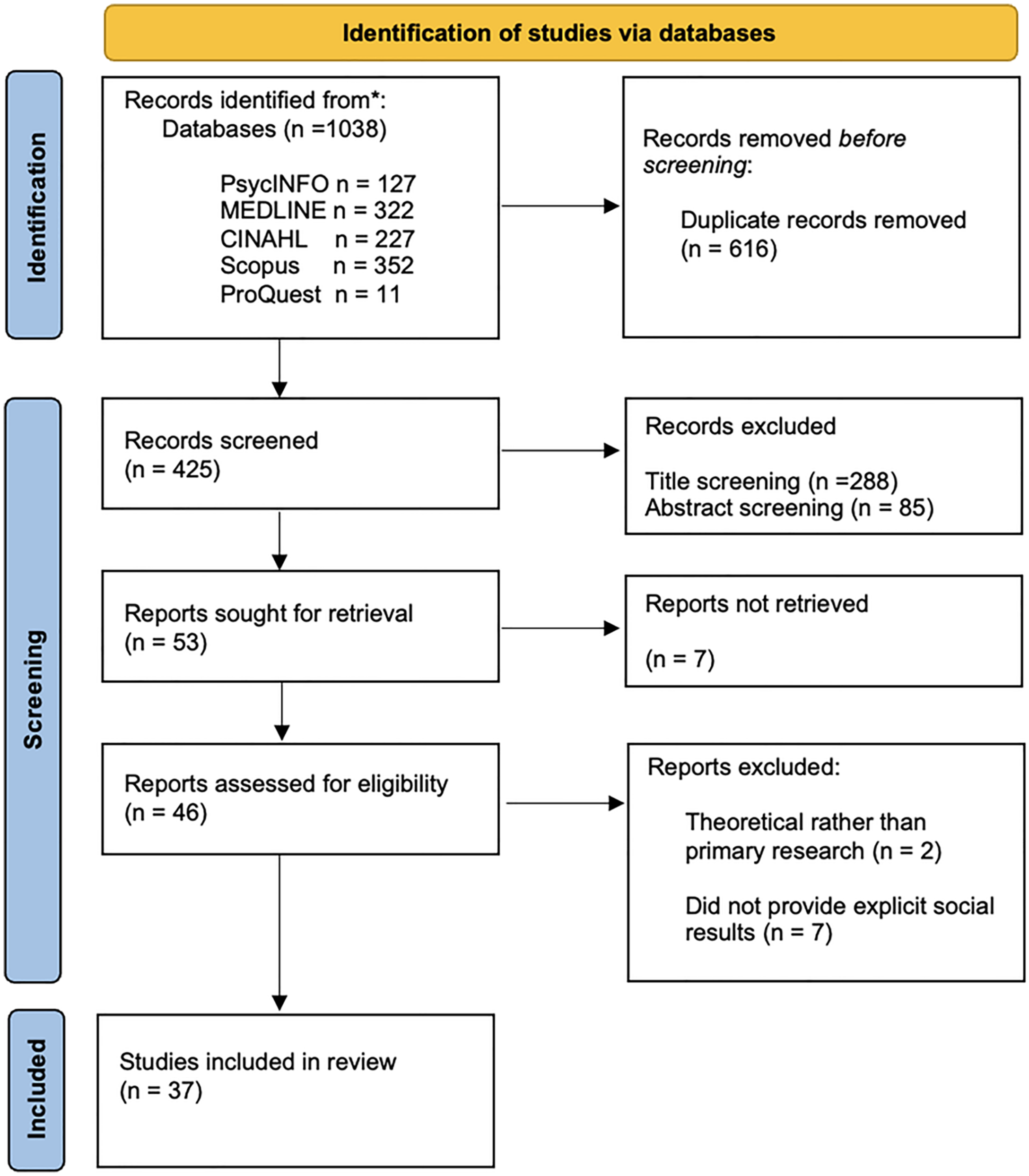

Figure 1. PRISMA flowchart adapted from Page et al. (2021) [22].
Note: Snowball searching and citation tracking were not conducted as part of the search strategy. The final search was conducted on 7th May 2024.

Table 2. Summary of study characteristics.

Study (AU, year)	Study design	Country	Description of participants	Neurodegenerative condition researched	Sample size N= (F=, M=)	Activity details	Mode of delivery	Intervention setting
Abell et al. 2017.	Mixed methods Surveys and interviews	Australia	Individuals with a neurodegenerative condition	Parkinson's disease	$N = 11$ ($F = 3$, $M = 8$)	Choir singing	In person	Community
Ashour. 2016.	Mixed methods Surveys and interviews	Kuwait	Individuals with a neurodegenerative condition	Multiple Sclerosis	$N = 16$ ($F = 12$, $M = 4$)	Exercise	In person	Community
Bek et al. 2022.	Mixed methods Surveys and thematic analysis of open questions	USA	Individuals with a neurodegenerative condition	Parkinson's disease	$N = 178$ ($F = 44$, $M = 134$)	Dance	Online	At home
Berardi et al. 2022.	Quantitative Surveys	Italy	Individuals with a neurodegenerative condition	Parkinson's disease	$N = 17$ ($F = 11$, $M = 6$)	Equine therapy	In person	Community
Brittle et al. 2008.	Quantitative Surveys	UK	Individuals with a neurodegenerative condition	Multiple Sclerosis Parkinson's disease	Multiple Sclerosis $N = 16$ ($F = 13$, $M = 3$) Parkinson's disease $N = 32$ ($F = 0$, $M = 32$)	Conductive education	In person	Community
Brown et al. 2012.	Qualitative Interviews and focus groups	Canada	Individuals with a neurodegenerative condition	Multiple Sclerosis	$N = 8$ ($F = 5$, $M = 3$)	Aqua fitness	In person	Community
Carroll et al. 2023.	Qualitative Focus groups	Australia	Individuals with a neurodegenerative condition	Parkinson's disease	$N = 5$ ($F = 3$, $M = 2$)	Dance	In person	Community
Cattaneo et al. 2019.	Quantitative Surveys	Italy	Individuals with a neurodegenerative condition	Parkinson's disease Multiple Sclerosis	Parkinson's disease $N = 32$ Multiple Sclerosis $N = 33$	Combined education and exercises Exercises only	Hybrid	Mixture of at home and community
Duret et al. 2022.	Quantitative Surveys	France	Individuals with a neurodegenerative condition	Multiple Sclerosis	$N = 13$	Exercises	In person	Community
Fakolade et al. 2017.	Qualitative Thematic analysis of healthcare worker's notes	UK	Healthcare professional	Multiple Sclerosis	$N = 86$	Three groups: Tele-rehabilitation alongside physical activity Fatigue management plus physical activity. Social support and generic health information	Online	At home
Foster et al. 2013.	Quantitative Surveys	USA	Individuals with a neurodegenerative	Parkinson's disease	$N = 52$	Tango dancing vs no intervention	In person	Community
Frich et al. 2014.	Qualitative, interviews and focus groups	Norway	Individuals with a neurodegenerative Family caregivers Healthcare professionals	Huntington's disease	Huntington's disease $N = 11$ ($F = 6$, $M = 5$) Caregiver $N = 9$ ($F = 4$, $M = 5$) Professionals $N = 15$ ($F = 13$, $M = 2$)	Group-based residential rehabilitation program	In person	Community
Gulliver et al. 2021.	Mixed methods Surveys and interviews	Australia	Individuals with a neurodegenerative Family caregivers Healthcare professionals	Dementia (including Alzheimer's disease)	Dementia $N = 15$ ($F = 6$, $M = 9$) Caregiver $N = 3$ ($F = 1$, $M = 2$) Professionals $N = 6$ ($F = 6$, $M = 0$)	Music engagement	In person	Community

(*Continued*)

Table 2. Continued.

Study (AU, year)	Study design	Country	Description of participants	Neurodegenerative condition researched	Sample size N= (F=, M=)	Activity details	Mode of delivery	Intervention setting
Hale et al. 2013.	Quantitative Surveys	New Zealand	Individuals with a neurodegenerative Healthcare professional	Multiple Sclerosis	$N=27$ ($F=23$, $M=4$)	Physical activity	In person	Mixture of at home and community
Hawkins et al. 2018.	Mixed methods Surveys and focus groups	USA	Individuals with a neurodegenerative	Parkinson's disease	Yoga $N=18$ Control $N=12$	Yoga	In person	Community
Humphrey et al. 2020.	Qualitative Interviews	USA	Individuals with a neurodegenerative condition	Parkinson's disease	$N=10$ ($F=3$, $M=7$)	Non-contact boxing	In person	Community
Jongen et al. 2014.	Qualitative Observation	Netherlands	Individuals with a neurodegenerative condition	Multiple Sclerosis	$N=44$ ($F=35$, $M=9$)	Social cognitive programme	In person	Community
Kalina. 2015.	Qualitative Interviews	USA	Individuals with a neurodegenerative condition	Multiple Sclerosis	Control $N=40$ ($F=30$, $M=10$) Experimental $N=51$ ($F=38$, $M=13$)	Social and educational activities	In person	Community
Leavitt et al. 2020.	Mixed methods Surveys and interviews	USA	Individuals with a neurodegenerative condition	Multiple Sclerosis	$N=24$ ($F=17$, $M=7$)	eSupport or eJournal telehealth support groups	Online	At home
Lin et al. 2024.	Qualitative Focus groups	Canada	Individuals with a neurodegenerative condition	Parkinson's disease	$N=9$ ($F=6$, $M=3$)	Non-contact boxing	In person	Community
MacCosham et al. 2019.	Qualitative Interviews	Canada	Individuals with a neurodegenerative condition	Parkinson's disease	$N=12$ ($F=5$, $M=7$)	Boxing	In person	Community
Marrow et al. 2020.	Qualitative Interviews	USA	Individuals with a neurodegenerative condition Caregivers Healthcare professionals	Multiple Sclerosis	Multiple Sclerosis $N=95$ Caregivers $N=26$ Professionals $N=44$	Multiple Sclerosis adult day programmes	In person	Community
McDermott et al. 2014.	Qualitative Focus groups and interviews	UK	Individuals with a neurodegenerative condition Family caregivers Care home staff Music therapists	Dementia	Dementia $N=16$ Caregivers $N=29$ Care home staff $N=5$ Therapists $N=8$	Music therapy	In person	Community
Merali. 2015.	Qualitative Interviews	Canada	Individuals with a neurodegenerative condition Family caregivers	Multiple Sclerosis	Multiple Sclerosis $N=4$ ($F=3$, $M=1$) Caregivers $N=4$	Exercise	In person	Community
Motl et al. 2011.	Quantitative Surveys	USA	Individuals with a neurodegenerative condition	Multiple Sclerosis	$N=48$ ($F=43$, $M=5$)	Physical activity education website	Online	At home
Morris et al. 2021.	Qualitative Interviews	Australia	Individuals with a neurodegenerative condition	Parkinson's disease	$N=12$ ($F=9$, $M=3$)	Dance	Online	At home
Pappa et al. 2017.	Mixed methods Surveys and interviews	USA	Individuals with a neurodegenerative condition Family caregivers	Parkinson's disease	Parkinson's disease $N=27$ ($F=11$, $M=16$) Caregivers $N=6$ ($F=4$, $M=2$)	Self-management programme	In person	Community
Pérez et al. 2011.	Quantitative Surveys	Spain	Individuals with a neurodegenerative condition	Multiple Sclerosis	$N=26$ ($F=17$, $M=9$)	Resistance exercises	In person	Community
Russell et al. 2023.	Qualitative Interviews	UK	Individuals with a neurodegenerative condition	Multiple Sclerosis	$N=17$ ($F=14$, $M=3$)	Social cognitive theory and exercise	In person	Community
Santini et al. 2022.	Mixed methods Surveys and interviews	Italy	Individuals with a neurodegenerative condition	Parkinson's disease	$N=18$ ($F=7$, $M=11$)	Cognitive Stimulation therapy	Online	At home
Schultz-Kahwaty. 2016.	Qualitative Interviews	USA	Individuals with a neurodegenerative condition	Parkinson's disease	$N=10$ ($F=4$, $M=6$)	Dance	In person	Community

(*Continued*)

Table 2. Continued.

Study (AU, year)	Study design	Country	Description of participants	Neurodegenerative condition researched	Sample size N= (F=, M=)	Activity details	Mode of delivery	Intervention setting
Souza et al. 2016.	Qualitative Case study	Brazil	Individuals with a neurodegenerative condition	Parkinson's disease	*N* = 1 (*F* = 0, *M* = 1)	Exercise	In person	Community
Stegemoller et al. 2017.	Qualitative Interviews	USA	Individuals with a neurodegenerative condition	Parkinson's disease	*N* = 20 (*F* = 13, *M* = 7)	Group singing	In person	Community
Suh. 2013.	Mixed methods Interviews and Surveys	USA	Individuals with a neurodegenerative condition	Multiple Sclerosis	*N* = 68 (*F* = 56, *M* = 12)	Physical activity	Online	At home
Tamplin et al. 2024.	Qualitative Interviews	Australia	Individuals with a neurodegenerative condition	Parkinson's disease	*N* = 28 (*F* = 12, *M* = 16)	Group singing	Online	At home
Twomey and Robinson. 2010.	Qualitative Interviews	Ireland	Individuals with a neurodegenerative condition	Multiple Sclerosis	*N* = 11	Fatigue management group	In person	Community
Waldorff et al. 2012.	Quantitative Surveys	Denmark	Individuals with a neurodegenerative condition Primary caregivers	Alzheimer's disease	Alzheimer's disease *N* = 330 (*F* = 179, *M* = 151) Caregiver *N* = 330 (*F* = 220, *M* = 110)	Psychosocial intervention	Hybrid	Mixture of at home and community

Table 3. Specific interventions in the included articles.

Intervention category	Specific intervention	Frequency
Social	Singing	3
	Telehealth	2
	Group-based day programme	2
	Music engagement	3
	Social cognitive can-do programme	1
Physical	Resistance and endurance training	7
	Cardiovascular	1
	Dance	5
	Aqua fitness	1
	Yoga	1
	Boxing	3
Education	Conductive education	1
	Educational activities, e.g., sessions centred around discussions of various topics	3
	Exercise and health education	4
Therapeutic	Equine therapy	1
	Self-management programme	1
	Cognitive Stimulation therapy	1
	Psychosocial intervention	1

Note: The total frequency may exceed the number of articles included because some interventions span multiple categories.

Interventions and activities identified

The review identified a wide array of interventions aimed at enhancing social participation and connectedness among individuals with neurodegenerative conditions. These interventions were categorised into several broad types, including physical activities, social activities, educational activities, and therapeutic activities. Activities within these broad types might include:

- Physical activities: Included community-based classes with a variety of exercises such as resistance and endurance training, dance, and yoga, aiming to improve physical fitness and overall wellbeing, with resistance training being the most common.
- Social activities: Predominantly involved group-based interventions like singing and music engagement, aiming to foster social connections.
- Educational activities: Focused on health education and discussions, including specific programs like Conductive Education.
- Therapeutic activities: Encompassed interventions focused on cognitive and emotional well-being, aiming to improve mental health, enhance cognitive functioning, and provide psychological support.

Specific detail on each intervention is provided in Table 3.

Thematic synthesis

The thematic synthesis of the included articles revealed several key themes and sub-themes that encapsulate the various interventions designed to promote social participation and connectedness among individuals with neurodegenerative conditions. This section presents a detailed exploration of these themes. All 37 articles discussed the theme of intervention details, 23 articles discussed the theme of theoretical frameworks guiding the interventions, and finally 26 articles discussed the theme of evaluations (Supplemental Materials 2). These themes were derived from a comprehensive synthesis of the study data and provide a holistic view of the current landscape of interventions in this field.

Theme 1: intervention details

The first theme, Intervention Details, refers to the specific activities, strategies, or structures implemented across interventions.

Additional support. Many interventions included additional support mechanisms for family caregivers [23–28], intervention facilitators [29–31], and the participants [23,26–29,31–43]. These support mechanisms were found to enhance the intervention's effectiveness by fostering a sense of community and providing necessary assistance to both participants and facilitators [23–44].

The most common additional support for carers and facilitators included educational sessions [23,24,26–31]. Whilst both carers and facilitators had access to additional educational support, caregivers were also supported via virtual and in-person counselling sessions which aimed to offer emotional support [23,27]. For facilitators, additional support took a logistical and educational form such as having advisory groups [29,31]. This logistical additional support for facilitators also included virtual weekly meetings amongst other facilitators [30].

For the individuals with a neurodegenerative condition, additional support tended to focus on blogs, websites, and written plans in which participants could easily access resources whenever suited the individual [23,30,31,34,35,40,43]. Moreover, the use of forums and update calls between participants and facilitators were seen to be beneficial and were only used in digital interventions. This communication was not solely based on the intervention, and participants were encouraged to use it for social benefits to promote a sense of community [28,29,34–36,43]. Finally, printed instructions, handbooks, diaries, and audio video materials were used to aid participants [28,29,31–35,43]

Intervention types. The most common intervention type was physical activities [24,27,29,30,33,34,38,41,43,45–54]. These interventions encompassed a variety of activities, such as resistance and endurance training [33,41,45,48,52–54], cardiovascular exercise [34], dance [24,27,30,47], aqua fitness [46], yoga [49], and boxing [38,50,51]. Individualised fitness plans were appreciated by many participants [30,34,38,41]. These tailored physical activities provided participants with opportunities to enhance their fitness at their own pace, while also continuing to foster social connections [30,34,38,41].

Educational interventions included a range of activities aimed at enhancing knowledge and skills. These interventions varied from general educational activities, such as discussion sessions on various topics [26,36,55], to more specialised programmes like conductive education [23], and health education [33,41,43,48]. The focus of these interventions was on empowering participants with information and practical skills that could improve their quality of life.

Social interventions focused on fostering interaction and community engagement. Singing groups provided a communal activity that encouraged regular social interaction and emotional expression [31,32,42]. Albeit similar, music engagement interventions included activities that involved active participation in music-making or listening, promoting social and emotional well-being [31,44,56]. Furthermore, group-based day programmes and socialisation programmes offered structured activities within a group setting, facilitating social interaction and community building [36,39]. The use of day groups was also remarked as beneficial to caregivers, by offering a form of respite [39].

The final theme was therapeutic interventions. These interventions were designed to provide specific therapeutic benefits through targeted activities [28,33,57,58]. Cognitive Stimulation Therapy focused on enhancing cognitive function through structured group exercises using cognitive training activities [58]. Psychosocial Interventions aimed at improving mental health and social well-being through approaches including counselling sessions, telephone support calls, and group education classes [28]. Equine Therapy utilised interactions with horses for psychological and physical benefits by offering tactile and emotional stimulation [57]. Self-Management Programmes empowered participants to manage their conditions through education and practical strategies [33]. These therapeutic interventions addressed both mental and physical health needs, offering holistic support to individuals with neurodegenerative conditions [28,33,57,58].

Intervention leadership. The leadership of the intervention was diverse, involving healthcare professionals, mixed leadership models, and trained facilitators. The type of leadership often influenced the structure, delivery, and perceived effectiveness of the interventions. Interventions that were led by healthcare professionals tended to have more structured and clinically oriented activities [28,29,33,41,48,58]. Healthcare professionals ranged from nurses [28], physiotherapists [29,33,41], occupational therapists [48], and therapists [58].

In contrast, interventions led by community facilitators, peers, or using mixed leadership models were often more flexible, participant-directed, and socially focused [30,31,33,38,46,52]. These approaches allowed greater responsiveness to individual preferences. Some studies noted that mixed or peer-led approaches encouraged a sense of shared ownership and group cohesion, which positively influenced participants' motivation and retention [30,38].

Recruitment methods. Recruitment methods varied widely. Methods included community outreach [24,25,29,32,42,46,47,52] such as distributing posters, convenience sampling of easily accessible participant pools [30,41], online recruitment [25,27,31,40,41,43,56], recommendations from healthcare professionals or peers [32,42,46], and recruitment via specialised centres [24–26,29,31,32,36,38,42].

Structure. The interventions included in this review varied widely in terms of duration, frequency, group size, and session length [23–59]. Some interventions were short-term, lasting just a few weeks [23,25,26,29–31,33,37,40–43,45,49,51–53,55–57], while others spanned several months [24,26,28,35], reflecting the need for flexibility based on the participants' availability and needs. Frequency also ranged from daily [20,36] to weekly sessions [24–26,29–38,40,42,45,47–59], with regularity often aimed at establishing routine and promoting consistent engagement among participants. Interventions varied in scale, with smaller interventions including less than 10 participants [1,13–16,25], while others involved larger groups of up to 20 or more participants [25,26,28,31,34,49,52,55]. Session lengths also differed, with some interventions lasting under an hour [17,19,22,24,25,27,29,33,35,37,38,41,44,48], while others extended beyond an hour [47,50], allowing for more comprehensive activities and deeper participant engagement.

Interventions with flexible formats were often reported as more engaging and empowering by participants, contributing to higher satisfaction and continued attendance [35,48,52,54]. Conversely, interventions with rigid schedules or prescriptive formats were sometimes described as less adaptable to individual needs [27,33], which could act as a barrier to implementation in community settings.

Theme 2: theoretical frameworks

The second theme, Theoretical Frameworks, examines the underlying theories that informed the design and implementation of the interventions. Theories were applied in varying ways, including to inform the structure and delivery of interventions, shape the underlying principles, or guide outcome evaluation. Some frameworks were explicitly stated and central to intervention design, while others were more loosely referenced as guiding philosophies.

Digital accessibility theories. Digital accessibility theories focused on removing barriers and improving accessibility in society [37,43]. These interventions utilised technology to bridge gaps caused by physical limitations, or geographical isolation. Articles highlighted the effectiveness of telehealth services and online support groups in overcoming mobility issues and connecting individuals remotely. Notably, interventions using digital accessibility as their theoretical grounding tended to focus on the newfound digital empowerment of participants; participants who may have been otherwise unable to attend social gatherings due to disabling factors in society were now able to be a part of a group collective and regain control of their social lives [37,43]. The theoretical contribution here was to reconceptualise technology not only as a tool, but as an enabler of participation by directly addressing the environmental barriers to social engagement. As such, these approaches ensured that participants could engage in social activities and health management programmes without being hindered by physical or societal constraints.

Person-centred theories. Person-centred theories emphasised the role of active facilitators [23,29,46,47] and the psychological benefits of personalised interventions [39,44,55,57,58]. These approaches focused on tailoring activities to individual needs or preferences and ensuring that participants felt valued and supported. Person-centred theories included the Person-Environment-Occupation Model [60]. This theory posits that the success of participation in an activity is due to interactions between individuals, their environment, and occupation [60]. In the interventions that drew on this model, the theory shaped both the structure and delivery of activities, placing emphasis on personal meaning, adaptability, and context-sensitive facilitation. The notion of participants also being facilitators was crucial in creating responsive and adaptive environments that could address the unique challenges faced by individuals with neurodegenerative conditions [23,29,46,47].

Interestingly, two musical interventions were grounded in theories of psychological benefits of personalised interventions. These interventions [44,56] were either based on the works of Dr John Diamond [61] or Prof. Tom Kitwood [62]; two leading theorists in rehabilitative musical therapies. Interventions using musical theory were based upon the notion that social relationships can be formed implicitly through musical interactions. The theoretical function here was to enhance emotional engagement and promote a sense of connection through non-verbal, affective channels such as rhythm and harmony.

Articles indicated that interventions designed around person-centred frameworks often resulted in higher satisfaction and better engagement among participants, as these programmes were more attuned to specific circumstances and goals.

Social theories. Social theories highlighted the importance of community engagement [25], improving self-efficacy [26,29,36,40,41,52], and socialisation [43,56]. These interventions aimed to strengthen community ties and encourage social interaction, thereby enhancing participants' sense of belonging and self-worth. Notably, many interventions [26,29,36,40,41,52] were grounded in Bandura's Social Cognitive Theory [63], which focuses on the significance of self-efficacy in motivating individuals to engage in activities and persist in these activities, despite any challenges that may occur. In these cases, the theory informed intervention goals, such as building confidence, setting realistic social goals, and creating opportunities for feedback and reinforcement.

Moreover, even when Bandura was not explicitly cited, such as in "blue prescription theory" [64], the notion of goal setting behaviour to drive self-efficacy was the main grounding feature of the intervention. The underlying theoretical assumption was that enhancing belief in one's ability to participate socially would translate into greater initiative and sustained engagement. By fostering supportive networks and facilitating meaningful social connections, these interventions sought to mitigate the effects of isolation and loneliness. Articles demonstrated that social theory-based interventions, such as group activities and community programmes, significantly contributed to improved mental health and social well-being of participants by promoting active social engagement and community support [25,26,29,36,40,41,43,52,56].

Theme 3: evaluations

The third theme, Evaluations, addresses the assessment of the interventions' effectiveness and efficiency.

Costs. Costs associated with implementing and taking part in interventions were very influential in several studies [29,31,34,35, 39,40,43,46,52,56,59].

Costs associated with participating were a significant consideration for many participants, especially those on disability benefits [46]. Financial barriers included membership fees, transportation costs, and other related expenses [39,40,46,52]. For instance, in one programme, participants recognised that a fellow participant struggled with travel expenses, so they collectively contributed to cover his costs to ensure he could attend [39]. Such monetary issues highlighted the financial strain some individuals faced in accessing these interventions [22,23,25,38]. However, some interventions did manage to negotiate continued discounted rates at certain gyms for people with disabilities, which alleviated some of the cost burdens for participants [34].

The financial demands of implementing the interventions were also substantial. Costs included resources for training facilitators, purchasing necessary equipment, and developing supportive materials [29,52,56]. Online interventions were often seen as cost-effective, particularly because of their potential for large-scale provision with minimal overheads [29,31,43,59]. One study even suggested that the online delivery would save roughly AUD$11 per week in money for participants [31]. Many of these interventions were funded, which meant that expenses such as instructor fees and subscription costs were covered [34,35,52]. However, certain activities, such as music therapy, required significant investment in hiring professionals, which could limit the scalability and wider adoption of these interventions [56]. Acknowledging these financial aspects is crucial for understanding the feasibility and sustainability of the interventions.

Improvements. Improvements suggested by participants and facilitators provided valuable insights into how the interventions could be enhanced [29,42,44,59]. These suggestions often focused on areas such as increasing the duration and frequency of sessions, incorporating more personalised activities, and improving accessibility [29,42,44,59]. Participants also recommended more diverse and inclusive social activities, better training for facilitators (particularly for digital platforms), and additional support resources [29,42,44,59]. More specific recommendations included offering written and visual materials to supplement home practice, such as printed lyrics, instructional videos, or mobile apps [59]. Some participants suggested the use of virtual reality and immersive technology to enhance engagement [59]. Others requested clearer organisation, such as formal registration systems to foster group cohesion, and better access to resources via a centralised portal [59]. Feedback also highlighted the need to respect individual preferences (such as musical choice) and avoid repetitive or tedious tasks (such as filling out physical activity diaries) [29,42,44,59]. Documenting these suggestions highlighted the need for ongoing adaptation and refinement of intervention strategies to better meet the needs and preferences of individuals with neurodegenerative conditions [29,42,44,59].

Retention. Retention rates were an important metric for evaluating the long-term engagement and success of the interventions [24,25,27,28,31,32,34,35,37,38,40,41,47,48,50,51,53,56]. High retention rates, 85% and over, indicated sustained interest and perceived value among participants [24,25,30–32,34,35,37,38,41,46–48,50,51,53], while lower rates seemed to be more prevalent in later stages of the interventions, highlighting potential areas for improvement in programme design and delivery [28,40,56]. Articles that reported high retention rates often featured engaging and flexible programme structures, strong facilitator support, and activities that resonated well with participants' interests and needs [24,25,30–32,34,35,37,38,41,46–48,50,51,53]. In contrast, interventions reporting lower retention commonly cited a range of factors, including health deterioration, bereavement, interpersonal or caregiving-related challenges, and financial or transport barriers [28,40,56]. These findings suggest that both individual-level and structural considerations play a key role in sustained engagement.

Accessibility. Accessibility emerged as a critical factor influencing participants' ability to engage with interventions [30,31,39,40,42,46,48,59]. The provision of regular time slots was particularly beneficial, allowing participants to plan their schedules around the intervention and ensuring consistent attendance [59]. However, not all aspects of accessibility were positive. Some participants encountered challenges at external community centres, where facilities were not fully equipped to accommodate their needs [39,46,48]. Additionally, participants who required one-on-one support felt excluded from group interventions that only had one instructor available, limiting their ability to fully participate [46].

Online interventions presented a mixed experience regarding accessibility. While some participants appreciated the flexibility to attend from anywhere [31,42], they also faced barriers such as the need for stable internet connections and proficiency with digital tools [30,40,48]. For some, these technological requirements were daunting and hindered their participation [30,40,48]. Conversely, others found online interventions liberating, as they eliminated the need for physical travel and enabled continued participation despite mobility limitations [31,42].

TIDieR framework

To provide a thorough analysis of the interventions in this review, the TIDieR framework [20] has been incorporated (Supplemental Materials 3).

The thorough documentation of intervention types, leadership roles, and additional support mechanisms indicates a high level of detail and consideration in planning and executing the included interventions. Similarly, the focus on theoretical frameworks, such as Bandura's Social Cognitive Theory, underscores the interventions' grounding in established research, which enhances their credibility and potential impact. Moreover, the articles' inclusion of evaluation components such as costs, improvements, and retention rates provide insights into the practical aspects of the interventions, offering a comprehensive view of their feasibility and sustainability. This detailed mapping ensured that the interventions in the articles included in this review are well-documented, facilitating their replication and adaptation in different contexts.

Discussion

This scoping review explored the breadth of interventions designed to promote social participation and connectedness among adults with neurodegenerative conditions. The interventions identified were diverse, encompassing a range of activities, theoretical underpinnings, and evaluative approaches, which were subsequently categorised into three overarching themes: Intervention Details, Theoretical Frameworks, and Evaluations.

Summary of evidence

This scoping review systematically mapped the available interventions designed to support social participation among adults with neurodegenerative conditions. The review identified a wide variety of interventions, categorised into physical activities, social activities, educational programmes, and therapeutic interventions. Physical activities [24,27,29,30,33,34,38,41,43,45–54] were the most frequently reported, with interventions such as resistance and endurance training, dance, and yoga being particularly common. Social activities primarily focused on group-based interventions like singing and music engagement [31,32,42], aiming to enhance social connections and reduce feelings of isolation. Educational programmes, including health education and discussions centred around becoming more active, were designed to improve knowledge and self-efficacy among participants [26,36,55]. Therapeutic interventions targeted cognitive and emotional well-being through activities such as cognitive stimulation therapy and psychosocial interventions [28,33,57,58].

The findings of this scoping review align closely with the review's aims, which were to identify the types of activities available to support social participation among adults with neurodegenerative conditions and to assess the use and effectiveness of digital technologies in this context. The review revealed that a wide range of interventions exists, with a strong emphasis on in-person activities. Moreover, the interventions that allowed for flexible delivery, participant input, or co-produced content were often perceived as more meaningful and empowering [35,48,52,54]. However, it also highlighted that the use of digital technologies, while promising, is not as prevalent as might be expected, given the increasing role of technology in healthcare and social engagement. This suggests a gap in the current research and practice, pointing to the need for further exploration and development of digital solutions to enhance accessibility and participation for those who may be physically isolated.

Recent research underscores the increasing role of digital technologies in enhancing accessibility and participation for individuals with mobility issues. Schueller [65] highlights the importance of technology-agnostic approaches in addressing loneliness and isolation, particularly within healthcare contexts. This aligns with the scoping review findings, which suggest that digital interventions are effective in promoting social connectedness for adults with neurodegenerative conditions. Technology solutions provide the flexibility needed to adapt interventions to diverse community settings and varying needs. Schueller's [65] work supports the notion that digital platforms can mitigate isolation by enabling engagement that is not limited by physical mobility.

Moreover, Weiner et al. [66] examine the use of digital platforms to deliver behavioural interventions to individuals with physical limitations. Their findings show that engagement and acceptability are key factors in the success of such interventions, echoing the results that emphasise the need for user-friendly digital platforms tailored to the specific needs of individuals with mobility challenges. This research illustrates how digital interventions can be optimised for accessibility, ensuring that participation is both practical and impactful. The insights from Weiner's [66] study reinforce the importance of designing digital solutions that account for user experience, increasing the likelihood of broad adoption and long-term effectiveness.

Junaedi et al. [67] explore the significance of digital literacy in enhancing social mobility and access to services, emphasising that closing the digital skills gap is crucial for enabling older adults to benefit from digital interventions. This is especially relevant in the context of neurodegenerative conditions, where individuals may face both physical and cognitive barriers to engagement. Digital literacy is typically lower among older adults [68–70], and this presents a significant challenge to the adoption of technology-based interventions. In the current review, several participants expressed discomfort or unfamiliarity with digital platforms, citing issues such as login difficulties, audio problems, and a general sense of being left behind [31]. One participant remarked, "We didn't grow up with the technologies that young people do today" [31], highlighting the generational gap in digital confidence. These findings underscore the importance of providing adequate training and support alongside digital interventions, to ensure their accessibility, effectiveness, and long-term sustainability for this population. Similar to our findings, Junaedi et al. [67] suggests that, without addressing the digital literacy gap, older adults with mobility or cognitive issues may be excluded from the advantages that digital interventions can provide. This insight is critical for the success of such interventions, indicating that supporting digital literacy alongside intervention deployment can significantly enhance both adoption and effectiveness.

As highlighted in the review's findings, the use of theoretical frameworks is crucial in guiding the development and implementation of digital interventions, particularly for behaviour change and improving accessibility. Yardley et al. [71] implemented the Person-Based Approach to intervention development, which has been discussed in some studies included in this review. This approach emphasises the importance of understanding users' needs and contexts to ensure that interventions are both acceptable and effective. The Person-Based Approach is particularly relevant in the context of older adults with neurodegenerative conditions, as it underscores the need to design interventions that are not only technologically accessible but also attuned to the cognitive, emotional, and social needs of this group [72]. By using frameworks that prioritise the user experience, interventions can better address the challenges associated with low digital literacy and enhance the effectiveness of digital solutions for improving social participation.

These studies provide substantial support for the conclusion that digital interventions can significantly enhance social connectedness and participation for individuals with neurodegenerative conditions. They also offer additional insights on the importance of digital literacy and platform engagement as critical factors in the effective implementation of these interventions. This emerging literature emphasises that while digital solutions offer significant potential, their success relies on overcoming challenges related to accessibility, user experience, and ongoing support for individuals with diverse needs.

Limitations

Only studies published in English were included, which may have resulted in the exclusion of relevant research conducted in other languages. This limitation could lead to a biased understanding of the global landscape of interventions, particularly in non-English speaking regions where different cultural approaches to intervention may exist.

Secondly, studies without empirical data were excluded in order to focus on interventions with measurable outcomes. However, this may have led to the omission of theoretical or conceptual studies that could offer valuable insights into intervention development, implementation, or contextual relevance.

Thirdly, additional sources of literature, such as snowball searching and citation tracking, were not utilised. Although the database search strategy was comprehensive, the exclusion of these supplementary methods may have limited the identification of grey literature or recently published studies not yet indexed.

Publication bias must also be considered. Since the review heavily relied on peer-reviewed literature, there is a possibility that studies with null or negative results are underrepresented, as these are less likely to be published. Moreover, publication bias might be particularly pronounced in studies focusing on digital interventions, where access to technology varies significantly across regions. The studies included in this review might primarily reflect interventions in regions with better digital infrastructure and access to technology, potentially overlooking challenges faced by populations in lower-resource settings where digital interventions may not be as feasible or effective.

Moreover, although the review protocol was published in an online journal, it was not registered in an open-access repository such as PROSPERO or the Open Science Framework. Registering the protocol may have further enhanced transparency and allowed for tracking of potential deviations.

Another limitation relates to the data extraction process, which was primarily conducted by the first author. While steps were taken to mitigate potential bias, such as piloting the extraction tool and reviewing a sample of studies with the wider team, subjectivity in interpretation cannot be entirely ruled out. Additionally, this review followed the Arksey and O'Malley framework [13], as outlined in the protocol [12]. While more recent guidance, such as that from the Joanna Briggs Institute (JBI), offers additional recommendations for conducting scoping reviews [73], these were not adopted in order to maintain consistency with the original protocol. This may be viewed as a limitation, as the JBI approach includes further refinements that could have enhanced methodological rigour.

Finally, the classification of neurodegenerative conditions remains an area of debate, particularly for conditions such as multiple sclerosis and dystonia. Multiple sclerosis is frequently described as a neuroinflammatory disorder due to its autoimmune mechanisms and relapsing-remitting course [74]. Similarly, dystonia is often regarded as a movement disorder or as a symptom secondary to other neurological conditions [75,76]. However, both are recognised in the ICD-11 as neurological diseases in their own right, with MS classified under demyelinating diseases (8A40) and primary dystonia listed as a distinct entity (8A02) [17]. Their inclusion in this review is therefore justified based on clinical classification, progressive functional decline, and the documented impact of these conditions on social participation.

Conclusions

The results of this scoping review underscore the diversity of interventions designed to enhance social participation among individuals with neurodegenerative conditions.

The implications of this review are broad, offering valuable insights for researchers, policymakers, and practitioners. For researchers, the review identifies key areas for future study, particularly in the development of digital interventions and the refinement of evaluation practices. For policymakers and practitioners, the findings provide evidence-based guidance on designing and implementing interventions that are both effective and scalable, ensuring that they meet the needs of individuals with neurodegenerative conditions across different contexts.

In conclusion, this scoping review provides a thorough overview of the current landscape of interventions aimed at enhancing social participation for individuals with neurodegenerative conditions. While the findings are encouraging, they also highlight the need for continued research and innovation, particularly in the realm of digital technologies. By addressing the gaps identified in this review, future interventions can be better equipped to support this vulnerable population, ultimately improving their quality of life and social connectedness.

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Authors' contributions

Conceptual work for the scoping review was led by KH, FW and DS. The scoping review protocol was developed and written by HT with input from all authors. HT undertook searches, screening and synthesis with input from all authors. HT drafted the review with editing input from all authors. All authors agreed the final draft.

Disclosure statement

The authors have a background in mix of social and clinical sciences including psychology (HT), medical sociology (FW), occupational therapy (DS) and physiotherapy (KH). None of the authors are living with a neurodegenerative condition, but two of the authors have been carers for individuals living with a neurodegenerative condition.

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Appendix A. General search strategy

	Search term	Boolean logic	Truncation/ wildcards	Limits (for all searches)	Databases searched (for all terms)
1	"Parkinson* disease"	Ti, OR	*	English language Date limit from 2008–Current Title (Ti) searches only	MEDLINE via OVID CINAHL (via EBSCO) PsycINFO (via OVID ProQuest Scopus
2	"Huntington* disease"	OR	*		
3	"Multiple Sclerosis"	OR			
4	"Motor neuron? disease"	OR	?		
5	"Alzheimer* disease"	OR	*		
6	Ataxia	OR			
7	Dystonia	OR			
8	Neurological	OR			
9	"Neurological condition*"	OR	*		
10	"Neurological disease"	OR			
11	Neurodegenerative	OR			
12	"Neurodegenerative condition"	OR			
13	"Neurodegenerative disease"	AND			
14	Leisure	Ti, OR			
15	"Physical activit*"	OR	*		
16	"Activit* of daily living"	OR	*		
17	Participat*	OR	*		
18	Interact*	OR	*		
19	Talk*	OR	*		
20	Engage*	OR	*		
21	Connect*	OR	*		
22	Recreation*	OR	*		
23	"Social participation"	OR			
24	Lonely	OR			
25	Loneliness	OR			
26	Alone	OR			
27	Connected*	OR	*		
28	Isolated	OR			
29	"Social connection"	OR			
30	"Social interaction"	OR			
31	"Social isolation"	OR			
32	"Social network"	OR			
33	"Social engagement"	OR			
34	Engagement	OR			
35	"Social wellbeing"	OR			
36	"Psychosocial wellbeing"	OR			
37	Wellbeing	AND			
38	Intervention*	Ti, OR	*		
39	Program*	OR	*		
40	Course*	OR	*		
41	Group	OR			
42	Class	OR			
43	Community	OR			
44	"Social program*"	OR	*		
45	"Social group"	OR			
46	Digital	OR			
47	Remote	OR			
48	Ehealth	OR			
49	Electronic	OR			
50	Online	OR			
51	Virtual	OR			
52	Internet	OR			
53	Telehealth	OR			

Appendix B. Data extraction instrument

Study (AU,YEAR, TI)	Study Design	Country	Description of participants	Neurodegenerative condition researched	Sample size N=(F=, M=)	Activity	Mode of delivery	Intervention setting	Key Findings

Abbreviations: *Au, Author; *TI, Title; *N = Overall number; *F = Number of Females; *M = Number of Males.

Appendix C. Reasons for article exclusion after screening

Study	Exclusion reason	Full citation
Baylor et al. (2012)	Does not provide explicit results for social variables	Baylor, C., Amtmann, D. and K. M, Yorkstone. 2012. A Longitudinal Study of Communicative Participation in Individuals with Multiple Sclerosis: Latent Classes and Predictors. *Journal of Medical Speech-Language Pathology* 20 (4), pp. 12–17.
Cugusi et al. (2014)	Does not provide explicit results for social variables	Cugusi, L., Solla, P., Zedda, F., Loi, M., Serpe, R., Cannas, A., and Marrosu, F., et al. 2014. Effects of an adapted physical activity program on motor and non-motor functions and quality of life in patients with Parkinson's disease. *Neurorehabilitation* 35 (4), pp. 789–94.
Farina et al. (2015)	Only included a proposed framework and background to the topic.	Farina, E., Villanelli, F., Baglio, F. 2015. *Intervention Program Mediated by Recreational Activities and Socialization in Groups for PWA with Alzheimer's Disease*. Söderback, I. (eds) International Handbook of Occupational Therapy Interventions. Springer, Cham. https://doi.org/10.1007/978-3-319-08141-0_56
Greany et al. (2014)	Does not provide explicit results for social variables	Greany, J. F., Hussey, E., Ceder, B. 2014. A university based physical activity program for individuals with parkinson's disease. *Cardiopulmonary Physical Therapy Journal* 25(4), pp. 122.
Hallberg et al. (2013)	Does not provide explicit results for social variables	Hallberg, L., Mellgren, E., Hartelius, L., and Ferm, U., 2013. Talking Mats in a discussion group for people with Huntington's disease. *Disability and Rehabilitation: Assistive Technology* 8 (1), pp. 67–76.
Kalina et al. (2018)	Does not provide explicit results for social variables	Kalina, J. T., Hinojosa, J., Strober, L., Bacon, J., Donnelly, S., Goverover, Y. 2018. Randomized Controlled Trial to Improve Self-Efficacy in People With Multiple Sclerosis: The Community Reintegration for Socially Isolated Patients (CRISP) Program. *Am J Occup Ther* 72(5). DOI: 10.5014/ajot.2018.026864
Porter et al. (2011)	Does not provide explicit results for social variables	Porter, S., Mazonson, N. and Tickle-Degnen, L. 2011. Supporting social participation in individuals with Parkinson's disease. *OT Practice* 16, pp. 17–18.
Suh et al. (2015)	Does not provide explicit results for social variables	Suh, Y., Motl, R. W., Olsen, C., Joshi, I. 2015. Pilot Trial of a Social Cognitive Theory-Based Physical Activity Intervention Delivered by Nonsupervised Technology in Persons With Multiple Sclerosis. *Journal of Physical Activity & Health* 12 (7), pp. 924–30. DOI: https://doi.org/10.1123/jpah.2014-0018
Thomson et al. (2015)	Proposed framework for future research	Thomson, A., Rivas, C., and Giovannoni, G. 2015. Multiple Sclerosis outpatient future groups: improving the quality of participant interaction and ideation tools within service improvement activities. *BMC Health Services Research* 15 (1), pp. 1–11. DOI: 10.1186/s12913-015-0773-8