

# Patient Education and Counseling

## A Parkinson care-coordinator may make a difference: A scoping review on multi-sectoral integrated care initiatives for people living with Parkinson's disease and their caregivers

--Manuscript Draft--

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<b>Abstract:</b>	<p><b>Objective:</b> To identify multi-sectoral integrated care initiatives for people with Parkinson's disease and caregivers.</p> <p><b>Method:</b> Following the Matrix Method we created a synthesis of literature across methodological approaches. The search was conducted in four databases until June 2022, and included studies focusing on multi-sectoral integrated care initiatives, and how they helped people with Parkinson's disease and caregivers in everyday living.</p> <p><b>Results:</b> The search yielded 5921 articles of which nine were included. We identified four topics describing characteristics of multi-sectoral integrated care initiatives: 1) Peer-support, 2) Personalised care plan, 3) One-off initiatives limited in time and 4) Presence of a coordinator. And four topics describing how the initiatives helped in everyday living: 1) Confidence, trust and support, 2) Positive changes in health outcomes, 3) Quality of life, coping skills &amp; psychosocial adjustment, and 4) A strengthened multi-agent collaboration and personalised assistance.</p> <p><b>Conclusion:</b> Multi-sectoral integrated care initiatives should be ongoing offers, and include a Parkinson care-coordinator, who can enhance multi-sectoral communication and an individualised approach to information about resources responsive to evolving needs at different disease stages.</p> <p><b>Practice implications:</b> Initiatives should be multidisciplinary, multi-sectoral and aimed at people with Parkinson's disease and caregivers, preferably facilitated by a care-coordinator to promote cross-sectoral communication.</p>
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## ***PATIENT EDUCATION AND COUNSELING***

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**Cover letter**

Dear Editors

Please consider the revised manuscript entitled, "A Parkinson care-coordinator may make a difference: A scoping review on multi-sectoral integrated care initiatives for people living with Parkinson's disease and their caregivers".

As requested the abstract is now placed in the manuscript text before the Introduction.

Please do not hesitate to contact us again, if you have further comments/questions.

Sincerely,

Louise Buus Vester, Anitha Haahr, Tove Lise Nielsen, Sandra Bartolomeu Pires & Mari Carmen Portillo

**Response to reviewers' comments**

<b>Reviewer #1</b>	<b>Respons</b>
<p>The authors adequately addressed my suggestions. A clarification is needed for the term "FC's" in the next sentence of the discussion section.</p> <p>Peer-support was identified as an important core characteristic, where PwPD and FC's could share experiences of everyday life with PD. Thus, this could be a way of gaining more knowledge of coping strategies, support and reduced feeling of loneliness, thereby enhancing QoL 40.</p>	<p>Thank you for your comment. The term "FC's" in the sentence of the discussion section has been altered to "caregivers", as this is the terminology we have been used throughout the manuscript.</p>

## **Highlights**

- Parkinson's disease poses challenges that impact everyday living.
- A multi-sectoral integrated care approach is needed at different disease stages.
- A coordinator and peer-support are core characteristics of multi-sectoral care.
- Ongoing multi-sectoral care initiatives may maintain positive health outcomes.
- A coordinator may facilitate an open-door approach and cross-sectoral communication.

## **A Parkinson care-coordinator may make a difference: A scoping review on multi-sectoral integrated care initiatives for people living with Parkinson's disease and their caregivers.**

### **Abstract**

**Objective:** To identify multi-sectoral integrated care initiatives for people with Parkinson's disease and caregivers.

**Method:** Following the Matrix Method we created a synthesis of literature across methodological approaches. The search was conducted in four databases until June 2022, and included studies focusing on multi-sectoral integrated care initiatives, and how they helped people with Parkinson's disease and caregivers in everyday living.

**Results:** The search yielded 5921 articles of which nine were included. We identified four topics describing characteristics of multi-sectoral integrated care initiatives: 1) Peer-support, 2) Personalised care plan, 3) One-off initiatives limited in time and 4) Presence of a coordinator. And four topics describing how the initiatives helped in everyday living: 1) Confidence, trust and support, 2) Positive changes in health outcomes, 3) Quality of life, coping skills & psychosocial adjustment, and 4) A strengthened multi-agent collaboration and personalised assistance.

**Conclusion:** Multi-sectoral integrated care initiatives should be ongoing offers, and include a Parkinson care-coordinator, who can enhance multi-sectoral communication and an individualised approach to information about resources responsive to evolving needs at different disease stages.

**Practice implications:** Initiatives should be multidisciplinary, multi-sectoral and aimed at people with Parkinson's disease and caregivers, preferably facilitated by a care-coordinator to promote cross-sectoral communication.

### **1. Introduction**

Parkinson's disease (PD) is a common neurodegenerative disease, with the main motor features being resting tremor, bradykinesia, rigidity and impairment of gait<sup>1</sup>. The prevalence of PD is 1-2 per 1,000, it affects approximately 1% of the population above 60 years<sup>2</sup> and increases by age<sup>3</sup>. The treatment of PD is symptomatic and levodopa therapy is considered most effective when treating motor symptoms<sup>4</sup>. Non-motor symptoms are also common in PD, and can more often than motor symptoms lead to changes in quality of life (QoL)<sup>5</sup>. Among others, non-motor symptoms include sleep disturbances, pain, autonomic dysfunction which covers gastrointestinal, urinary and sexual

dysfunction, but also dementia and other neuropsychiatric symptoms such as depression and apathy are common. The prevalence and impact of non-motor symptoms increases with age<sup>3</sup>.

The complexity, of the disease and lack of neuroprotective treatment options poses varying challenges for people with PD (PwPD) and their caregivers. In this article, caregivers refer to informal carers such as relatives and friends. In many cases, PD has a negative effect on QoL for both PwPD and caregivers<sup>6-9</sup>. Balash et al.<sup>7</sup> report caregiver stress in spouses of PwPD and emphasise the impact it may have on their psychological and physical health. Additionally, qualitative studies exploring everyday life with PD from the perspective of PwPD and caregivers support that PD has a profound impact on daily life. One main challenge is living with the unpredictability of the disease, affecting the ability to actively engage in activities in everyday life; another challenge is the physical and psychosocial consequences of living with PD<sup>10-12</sup>. Other important challenges are changes in identity and more importantly worries about the future<sup>11,13,14</sup>.

The complexity of PD thus requires a management approach that integrates multidisciplinary teams, levels of care and systems of support in the community. Integrated care is defined by WHO 2016, p. 2 as *“health services that are managed, discussed and delivered so that patients can make the choices necessary to receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course.”*<sup>15</sup>.

There has been a growing interest in the literature to illustrate the need and relevance of integrated care for people with progressive conditions, like PD<sup>16,17</sup>. Lidstone, Bayley and Lang<sup>18</sup> argue that multidisciplinary care should be the gold standard for chronic disease management. They also highlight that all care should be integrated vertically, in disease groups as well as horizontally, across health care systems<sup>18</sup>. Radder and colleagues<sup>16</sup> emphasise “the patient-as-partner” as an essential feature of a multidisciplinary approach. Furthermore, the progressive nature of PD calls for attentiveness towards disease stage and how this impacts the need for support and education. It seems that, at present, no PD program is available that may be adopted to disease-stage<sup>19</sup>.

A multi-sectoral approach is understood as the collaboration between various stakeholder groups from macro, meso and micro societal levels of action to achieve policy, health and practice related outcomes<sup>20</sup>. The foundations of this collaboration are based on the principles of assistance, support, sharing and linking, benefiting from the strengths of working together towards the promotion of



better living with PD<sup>20</sup>. Studies with a multi-sectoral integrated approach to care for PD with an emphasis on how such interventions may impact everyday life management are, however, less apparent, and no literature review has been found to summarise this knowledge. Thus, the objective of this scoping review is to identify multi-sectoral integrated care initiatives for PwPD and their caregivers based on the following review questions.

## **Review Questions**

What characterises multi-sectoral integrated care initiatives in PD care documented in the research literature, and how can these help PwPD and caregivers in their everyday living?

## **2. Methods**

A review of the literature was conducted using The Matrix Method developed by Garrard<sup>21</sup>. This approach allows researchers to include qualitative and quantitative literature on the topic of interest and conduct an integrated narrative synthesis across studies<sup>21</sup>. The construction of the scoping review was further refined using the Joanna Briggs Institute (JBI) methodology for scoping reviews<sup>22</sup>. The review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-analysis extension for Scoping Reviews (PRISMA-ScR; Appendix A)<sup>23</sup>.

### **2.1 Search strategy**

A comprehensive systematic search was performed from September to November 2020 and repeated June 2022. A three-step search strategy was used to identify and map the existing evidence on multi-sectoral integrated care initiatives and how they helped PwPD and caregivers in everyday life. The Population, Concept and Context framework (PCC) was used to guide the structuring of the review questions and to frame the inclusion criteria<sup>24</sup>.

The first step encompassed an identification of index terms which took place in an iterative process, starting with an initial unstructured broad search in databases. Secondly, database searches were undertaken in collaboration with a research librarian. An initial search in MEDLINE/EBSCO using the identified index terms refined the keywords. Titles, abstracts and index terms were analysed and relevant terms were included in the PCC framework. Subsequently, the revised framework was used to search in CINAHL Complete/EBSCO. New index terms and keywords were identified and included in the PCC framework. This search strategy was repeated in APA PsycINFO/EBSCO and EMBASE, whereby all potential index words and keywords were identified in all of the databases.

Thirdly, final and comprehensive searches using all identified index terms and keywords in free text, were conducted in the EBSCO and EMBASE databases. The search terms were combined using the Boolean operators OR/AND. An example of the full electronic search strategy in EBSCO, is presented in appendix B.

## **2.2 Inclusion and exclusion criteria**

We included articles that reported multi-sectoral integrated care initiatives aimed at improving everyday living for PwPD and/or their caregivers, irrespectively of any comorbidity such as psychiatric diagnosis. Aligned with Garrard<sup>21</sup>, studies with different study designs were included to avoid exclusion of important sources of knowledge in an anticipated field of sparse literature. The articles had no restriction on publication dates. Inclusion- and exclusion criteria are displayed in Table 1.

[Insert Table 1]

## **2.3 Study selection**

All identified citations were transferred and duplicates removed within the citation management system Zotero<sup>25</sup>. First and second author screened the citations by title and abstract. When doubt arose, co-authors were involved. Subsequently, selected citations were screened for eligibility against the inclusion criteria and discussed among the authors to enhance rigour. Reviews were not included in full length but were screened for eligible primary studies.

## **2.4 Ethical considerations**

Ethical conduct when performing a literature review were followed, by analysing findings from the included articles with outmost caution and respect to the original context in which the articles were written<sup>26</sup>. All studies had obtained ethical approval from national institutional research ethics boards and/or had described relevant ethical considerations.

## **2.5 Synthesis using the review matrix**

The Matrix Method<sup>21</sup> was followed to enhance rigor in organising, analysing and creating a narrative synthesis of the literature with respect to different methodologies. A specific focus was on identifying content-specific characteristics of the supportive multi-sectoral integrated care initiatives and how they helped PwPD and their caregivers in everyday life.

We abstracted the articles, guided by the 4 step-process<sup>21</sup>: 1) Each article was read thoroughly. 2) Data was extracted from the findings and discussion sections of articles. Quantitative data were interpreted and constructed into qualitative statements and synthesized with qualitative data. 3) A list of topics was created to represent the extracted characteristics of the initiatives and they helped to improve everyday life for PwPD and caregivers. 4) All articles were re-read and analysed in regard to all identified characteristics to avoid missing out on important data.

### **3. Results**

#### **3.1 Study inclusion & quality assessment**

Database searches identified 5,921 citations, which after limitations and removal of duplicates resulted in 2,120 citations. After screening by title and abstract, 2,098 citations were excluded. The full text of 22 citations were assessed for eligibility against the inclusion criteria. The majority of citations were excluded due to no clear multi-sectorial approach (n=14). In total, eight articles were included and one additional article was retrieved through snowballing (by screening the articles' reference lists)<sup>27-35</sup>. The nine articles stemmed from six different main projects. A PRISMA flowchart<sup>23</sup> for tracking the numbers of articles throughout the review process, is shown in Figure 1.

[Insert Figure 1]

Quality assessment of each article was conducted by the authors in pairs of two - first, separately, then through mutual discussions of notes. Articles were assessed using either a critical appraisal checklist chosen according to study design from The JBI manual<sup>24</sup> or the Mixed Methods Appraisal Tool<sup>36</sup>. Generally, the included studies were found of good quality, and no articles were excluded based on the quality assessment. As it had no consequences the critical appraisal of included sources of evidence are not presented.

An overview of the included articles is presented in Table 2 and a description of their multi-sectoral care initiatives is detailed in Table 3.

[Insert Table 2]

[Insert Table 3]

The reported studies varied in design, objective, target PD population, multidisciplinary composition and multi-sectoral actions. Seven articles had a quantitative design, one a qualitative

design and one had a mixed-methods design. Three articles originated from one project<sup>27,32,34</sup> and two from another<sup>29,33</sup>.

The articles' objectives were to describe, evaluate and/or to contribute to further development of PD initiatives<sup>27-35</sup>. Every initiative was aimed at both PwPD and caregivers<sup>27-35</sup>, however, their target PD population was diverse, in regard to time since diagnosis and stage of PD. Some focused on people with advanced PD<sup>27,32,34</sup>, others included all stages of PD<sup>28-31,33,35</sup>. One initiative was also directed at stroke<sup>30</sup>, another was directed at various disorders related to PD, e.g. PD dementia, Lewy body dementia and atypical Parkinsonism<sup>27</sup>. All initiatives included different compositions of professionals specialised in PD, e.g. geriatricians, neurologists, nurses, occupational therapists, physiotherapists, psychologists, social workers, and specialists in medicine, psychiatry, sleep, speech and language<sup>27-35</sup>. Additionally, all initiatives had a clear multisectoral objective, e.g. by enhancing collaboration, coordination and/or cross-sectoral communication<sup>27-35</sup>.

The synthesis revealed a broad variety of topics, describing the multi-sectoral integrated care initiatives for PwPD and caregivers. Core characteristics of the multi-sectoral integrated care initiatives were described through four topics, likewise, areas of perceived improvements of everyday life for PwPD and caregivers were unfolded in four topics, as depicted with references in Table 4. The findings are shown in Figure 2.

[Insert Table 4]

[Insert Figure 2]

## **3.2 Core characteristics of care initiatives**

### **3.2.1 Peer-support**

Peer-support was a core characteristic, where PwPD and caregivers were given the opportunity to share their experiences with peers<sup>28-30,35</sup>. This enhanced PwPD's and caregivers' sense of community because their desires and fears were shared by others<sup>28</sup>. It also accommodated their social challenges and the psychosocial impact associated with PD, which had a positive impact on their social activities and emotional well-being and improved their self-confidence<sup>28,35</sup>. Peer-support gathered around leisure activities, e.g. dancing and singing, strengthened the bond between them and created a sense of being a family<sup>28</sup>. Kessler et al.<sup>29</sup> highlighted the importance of creating disease specific groups designed only for PwPD and their caregivers. Additionally, they

recommended cautiousness in gathering people across stages of the disease, as people with newly diagnosed PD may be prematurely confronted with the progression of the disease.

### **3.2.2 Personalised care plan**

A characteristic of some initiatives was the development of a personalised care plan, based on the problems and challenges experienced by PwPD and caregivers, indicating the need for referrals to relevant resources<sup>27,29,31–34</sup>. In the initiatives of Fleischer et al.<sup>27,32,34</sup> the comprehensive person-centred assessment and plan was based on a physical examination, medication and reconciliation and assessment of psychosocial needs and home safety. In the Comprehensive Care Clinic (CCC)<sup>31</sup>, the comprehensive care plan was developed based on the evaluation of meetings between PwPD and caregivers and all disciplines relevant to PD, to ensure coverage of both motor and non-motor symptoms<sup>31</sup>. In the IPCN<sup>29,33</sup>, the personal care plan was developed, based on the desire to ensure patient education, self-management support and structured clinical follow-up. Through collaborative shared decision-making, the top three care priorities and corresponding goals of the PwPD were identified and the necessary healthcare resources, selected by the patient, were made.

In all studies, the initiatives were directed at both PwPD and caregivers, if present<sup>27–35</sup>. Kessler et al.<sup>29</sup> and Vaughan et al.<sup>31</sup> stressed the importance of a holistic and person-centred approach to accommodate the variation in symptoms and care priorities experienced by PwPD and caregivers at every stage of the disease. They also accentuated the importance of offering all PwPD and caregivers information and assessment of motor and non-motor symptoms, mental health and education needs, regardless of their duration and stage of PD<sup>29,31</sup>. Kessler and colleagues<sup>29</sup> stress that although newly diagnosed PwPD may be distressed by the increased awareness of potential problems and challenges in their life ahead; this awareness may also facilitate discussions about PD symptoms and progression. Likewise, Vaughan et al.<sup>31</sup> argue that, awareness to symptoms not attributed to PD, could be addressed with targeted interventions. Generally, it was emphasized that tailoring information to patients' and caregivers' needs at varying stages of the disease is important for a person-centered care approach<sup>29,31</sup>.

### **3.2.3 One-off initiatives limited in time**

The initiatives were characterised by varying duration, type and frequency. The six months Integrated Parkinson's disease Care Network (IPCN)<sup>29,33</sup> offered an initial visit of approximately 90 minutes with a clinical care integrator to define the personal care plan as the basis for subsequent

healthcare system navigation; a one month follow-up telephone call to revise the care plan and facilitate additional support; a three months optional visit and a close-up visit evaluating the degree of completion of the care plan<sup>29,33</sup>. In the 12 months Home Visit Program (HVP)<sup>27</sup> and the further developed Interdisciplinary home Visits for Parkinson's disease (IN-HOME PD) initiative<sup>32</sup>, one visit was paid every four months, with follow-up phone calls two to eight weeks after each visit. Initially, the comprehensive care plan was conducted, and the necessary referrals made. In the following visits, the care plan was adjusted to any new needs<sup>27,32</sup>. The CCC<sup>31</sup> was a two-day evaluation of the PwPD and caregiver, where a comprehensive care plan was conducted based on a multidisciplinary assessment of motor and non-motor symptoms, which eventually was sent to the referring physician and primary care physician. The nine weeks psychoeducational initiative, of Navarta-Sánchez et al<sup>35</sup>, offered one weekly 90 minute session. Though unclear, the Saturdays-in-Motion (SIM)<sup>28</sup> appears to be a continuous offer for PwPD and caregivers, with monthly four-hour sessions, consisting of educational sessions, cognitive or physical rehabilitation and leisure activities. The Micro Ad-hoc Health Social Networks (uHSN)<sup>30</sup> was under development; dose and frequency was therefore unclear, including whether it was to be an ongoing offer.

Though most initiatives were one-time offers, studies accentuated the need for developing ongoing offers with follow-up or an open-door approach to accommodate the diverse symptoms and progression of PD<sup>29,33,35</sup>.

#### **3.2.4 Presence of a coordinator**

Three of the initiatives were led by a coordinator and different nomenclature was used such as a clinical care integrator<sup>29,33</sup>, nurse coordinator<sup>31</sup> and a social worker<sup>27,32,34</sup>. The coordinators were trained specialists in PD and had diverse, but multifaceted roles: From gatekeeper of the initiative<sup>31</sup>, to participating in the assessment of the PwPD and caregiver's situation<sup>27</sup>, to a more substantial role, where the coordinator was the key point for the success of the initiative<sup>29,33</sup>. In the study by Kessler et al.<sup>29</sup> PwPD and caregivers described the role of their clinical care integrator as crucial to the success of the initiative; the clinical care integrator facilitated the multi-sectoral integrated care approach by creating the linkage between sectors, coordinating referrals to community service providers and neurologists based on patients' symptoms and challenges<sup>28</sup>. In addition, the coordinator was available at all times, providing the needed assistance and advocacy in accessing resources<sup>29</sup>.

### **3.3 Improvement of everyday life with PD**

### **3.3.1 Confidence, self-management & support**

Three studies found improvements in PwPD and caregivers' experience of confidence, self-management and support<sup>28,29,33</sup>. Muñoz et al.<sup>28</sup> found that the peer-support had a positive impact on PwPD and caregivers' social activities and emotional well-being, which improved their self-confidence. Confidence and comfort were also experienced in the initiative of Kessler et al.<sup>29</sup>. The PwPD and caregivers accentuated the clinical care integrator's warm, empathic communication style and sensitivity to anxieties and concerns of stage of disease, which in particular helped newly diagnosed PwPD to feel less overwhelmed by the information about PD, thereby mitigating the emotional impact. Despite these findings, PwPD and caregivers expressed different levels of readiness for self-management. While some felt a sense of empowerment and active engagement in managing their health and life with PD, others needed the support from the clinical care coordinator to be an ongoing offer, as it was perceived as a security blanket for self-management and living with PD<sup>29</sup>. Patients who took part in the IPCN seemed more emotionally prepared for living with PD compared to those who hadn't participated in the initiative. Those who, prior to the initiative, were proactive in managing their condition and in seeking out resources, wanted more feedback on progress, whereas others reported benefitting from the increased awareness of services<sup>29</sup>. In the pilot evaluation of the IPCN<sup>33</sup>, improvements in the perception of support for chronic care and self-management was confirmed in both patients newly diagnosed with PD and patients with advanced PD. However, for the patients newly diagnosed with PD the improvements were not maintained at three months<sup>33</sup>.

### **3.3.2 Positive changes in health outcomes**

This section covers the initiatives' ability to improve health in PwPD and caregivers in relation to adjustment in medication, The Unified Parkinson's disease Rating Scale (UPDRS) scores, health utilisation and caregiver strain. In relation to adjustment of medication, Vaughan et al.<sup>31</sup> found that patients attending the CCC were more likely to be advised to adjust antidepressants and PD medications, though in the latter there was no significant difference between those who attended CCC and those who did not. Blanco et al.<sup>30</sup> found that uHSN improved patient medication management in 93% of the participants. Vaughan et al.<sup>31</sup> found a significant difference in the American Academy of Neurology (AAN) quality measures of PD assessment between PwPD seen in CCC compared to PwPD offered usual specialist care, with better result in the CCC group. An outcome in several of the studies was changes in UPDRS scores as a result of the initiative. Thus,

Vaughan et al.<sup>31</sup> found an improvement in UPDRS score from baseline to follow-up, although no significant between-group difference. Fleisher and colleagues<sup>34</sup> found that people with advanced PD who had received an IN-HOME-PD visit had a significantly worsened total UPDRS score over 1 year. In addition, health service utilisation remained either the same or decreased, and none was institutionalised during the study. However, the findings show that caregiver strain increased significantly in the same period<sup>32,34</sup>

### **3.3.3 Quality of life, coping skills & psychosocial adjustment**

Five of the initiatives sought to improve QoL, coping skills and psychosocial adjustment to improve everyday life for PwPD and caregivers<sup>28,32-35</sup>. Navarta-Sánchez et al.<sup>35</sup> found a significant improvement in QoL immediately after the intervention in PwPD in the intervention group as well as the control group. However, this was not maintained over time, nor was there any significant between-group difference at any point. In addition, no caregivers in either group improved their QoL at any point. Similarly, Mestre et al.<sup>33</sup> found that PwPD significantly improved their QoL. However, in contrast to Navarta-Sanchez et al.<sup>35</sup> the change pertained to the advanced group but not to the newly diagnosed group. In the study by Muñoz et al.<sup>28</sup>, 95,8 % of patients experienced improvements in QoL, indicating that participating in SIM may improve the QoL in PwPD. Improvements in QoL dimensions were related to an increased awareness of the PD symptoms and the disease itself, with improvements mainly within communication, bodily discomfort, emotional wellbeing and social stigma. Interestingly, in the studies by Fleischer and colleagues<sup>32,34</sup> there were no significant negative changes in the eight QoL domains, despite disease progression and the target group being people with advanced PD. In the study by Navarta-Sanchez et al.<sup>35</sup>, there was no improvement in coping skills in either group of patients, nor a significant difference between the groups. But caregivers in both groups improved their coping skills. However, this improvement was not maintained over time, nor was there a significant difference between the groups of caregivers. In relation to psychosocial adjustment, there was an improvement within both groups of PwPD and caregivers, though no between-group difference. The psychosocial adjustment was not maintained over time in any group.

### **3.3.4 A strengthened multi-agent collaboration and personalised assistance**

Several initiatives led to improvements in communication and multi-agent collaboration between PD specialists, PwPD and caregivers, which had positive influence on the PwPD and caregivers' everyday life<sup>28,30,31</sup>. In SIM, the collaboration and activities redefined the traditional patient-



physician relationship by creating a sense of community and the opportunity of learning about PD outside the routine clinical consultation. The bond between clinical experts, PwPD and caregivers motivated the PwPD adherence to treatment and altered the clinical experts' focus from limitations of the disease to abilities despite the disease<sup>28</sup>. In addition, collaborating with the same health professionals facilitated continuity of care, but also provided a respite from social isolation<sup>32</sup>. Vaughan et al.<sup>31</sup> found that the multidisciplinary team approach facilitated communication of findings and recommendations between PD specialists, which hindered potential conflicts to arise and instead enabled learning from each other. Regarding the uHSN<sup>30</sup>, patients and professionals agreed that the use of a social-based technological solution enhanced personalised assistance and care and enabled new communication channels between them and improvements in empathy, reciprocity and affective companionship for assistance and disease care. While the relationship within professionals and between patients and professionals showed an improvement, the impact on relationship within patients was less apparent, indicating a need to improve the relational network of patients (by defining patient profiles and patient groups) to increase levels of interaction and social relations<sup>30</sup>.

#### **4. Discussion and conclusion**

##### **4.1 Discussion**

The main findings from this review are that peer support, individualised care planning and a coordinator were considered to be beneficial aspects for supporting everyday life with PD, resulting in an initial improvement in QoL. In addition, the interventions improved communication among and between agents (health care professionals, patients and caregivers), and health outcomes and general issues were discovered and dealt with sooner than usually. Most importantly, it seemed that participants gained more confidence and enhanced self-management. The main feature of the personalised care plan entailed a holistic approach, dealing with both motor and non-motor symptoms. Personalised care planning is seen as a focus in other initiatives such as the Prime Parkinson model<sup>37</sup>, and it is an addressed and expressed need by newly diagnosed PwPD<sup>38</sup>. The unpredictable trajectory of PD poses challenges which in particular calls for a personal care plan, preferably built in cooperation with a health professional assigned as contact person<sup>38</sup>. Kang et al.<sup>39</sup>, unfold several indicators of empowerment in PwPD of which some are: self-management, knowledge, sense of meaning and access to health care, thus supporting the importance of personalised care and easy access to knowledge and health care. Peer-support was identified as an important core characteristic, where PwPD and caregivers could share experiences of everyday life

with PD. Thus, this could be a way of gaining more knowledge of coping strategies, support and reduced feeling of loneliness, thereby enhancing QoL<sup>40</sup>. However, as highlighted by Kessler et al.<sup>29</sup>, the organisation of peer-support should consider the vulnerability of in particular newly diagnosed when gathering PwPD across disease stages, to avoid them being prematurely confronted with the trajectory of the disease. Van Halteren and colleagues<sup>41</sup> suggest a model entailing five core elements to address individual's needs and preferences, which are care coordination, patient navigation, information provision, early detection of signs and symptoms through proactive monitoring, and process monitoring. These are elements which are also to be found in the studies included in this review and consideration of engaging in peer-support could be added.

The roles of the coordinator were described as manifold. One main feature was that all coordinators were trained and specialised within PD. The multiple tasks of the coordinator align with the findings in a recently published review by Munster and colleagues<sup>42</sup>, which illuminates the many and various tasks of a Parkinson nurse, being a specialised professional, with a significant role in a multidisciplinary care team. In particular, Munster et al.<sup>42</sup> highlight how the Parkinson nurse could facilitate communication between health professionals through a variety of channels. Thus, a coordinator, trained and specialised within PD, could be beneficial for ensuring integrated care pathways for PwPD. Lack of communication between agents in PD care management has, in several studies, been identified as impeding the quality of integrated care<sup>43-45</sup>. However, findings from this review support that initiatives targeting individualised care, with a multi-sectoral and interdisciplinary care model, do improve communication, between not only health professionals and PwPD and caregivers, but also among health professionals and social workers. Munster et. al also found that a task of the Parkinson nurse was to refer to resources available and relevant for the PwPD and caregivers<sup>42</sup>. Such resources have been identified by Nielsen et al<sup>46</sup>, who also emphasise that health services in PD are complex and need to be better coordinated. Other programmes were identified in our literature search, but did not fulfil the criteria of the review. Thus, the Patient Education Programme for Parkinson's disease targeting better living with PD, which is widely recognised, and known to increase QoL on a short-term basis<sup>47-49</sup>. The Dutch ParkinsonNet serves as a platform for healthcare professionals to access specialised knowledge about PD and for patients to access relevant professionals<sup>50</sup>. Bloem and colleagues<sup>50</sup> found the ParkinsonNet to be successful in terms of an increase in community-based specialised therapists and an increase in PD patients who received specialised treatment. Albeit lacking a multi-sectoral action, the focus in these interventions are to some extent similar to the focus of the interventions included in this review,

and they underline the need for coordinated multi-sectoral action. In this regard, it is also worth noting that PwPD in most interventions included in this review experienced an increase in QoL, however not lasting. Unfortunately, this was not the case for family caregivers who in some cases experienced a worsening of QoL when the disease progressed. Bearing in mind the described characteristics shows that most supportive multi-sectoral integrated care initiatives are time limited<sup>27,29,31,32,35</sup>. Nevertheless, all studies argue the need for offering ongoing supportive multi-sectoral integrated care initiatives/strategies to PwPD and caregivers. Thus, Navarta-Sánchez et al.<sup>35</sup> highlight that supportive multi-sectoral integrated care initiatives should be offered throughout the course of the disease in order to improve QoL in PwPD and caregivers and to maintain long-term positive behaviour and attitudes<sup>35</sup>. Recent qualitative studies support this need for integrated care initiatives from both PwPD and caregivers' perspectives<sup>45,51</sup>. Kessler et al.<sup>29</sup> suggested an open-door approach, because of the individual variation of when and how PwPD experience symptoms. Others have suggested to supplement the initiatives/strategies with counselling and education, follow-up calls, homework and individual home sessions, and booster sessions<sup>27,35</sup>. This may diminish fragmented care, reduce institutionalisation and caregiver strain<sup>27</sup>. These are important aspects to take into consideration when developing interventions for future multi-sectoral care.

This review integrates knowledge and research on supportive multi-sectoral integrated care initiatives for PwPD and their caregivers adding to the evidence on the subject. A limitation of this study is that the terminology found in the literature varied making it difficult to identify studies that were clearly multi-sectoral. To avoid excluding important knowledge, we included studies even though the aim of a particular study was not an exact match to our inclusion criteria, if the study did include interdisciplinary collaboration and was community based. Nevertheless, the limited literature with a clear multisectoral approach to PwPD and their caregivers must be considered a limitation of this study. Also, the strength of evidence concerning effectiveness of the interventions is weak, as none of the quantitative studies used a randomised design, considered the strongest design to determine the effectiveness of an intervention<sup>52</sup>. The collaborative and structured processes in conducting the literature search, the quality assessments and the analyses strengthened the review.

## **4.2 Conclusion**

Important main characteristics of a multi-sectoral intervention targeted at PwPD and caregivers were derived from this scoping review. They included having a coordinator with specialised

knowledge about resources, who could facilitate communication between sectors and agents. Initiatives should preferably have a personalised approach and entail peer-support activities. Quantitative as well as qualitative findings supported that initiatives with the abovementioned characteristics could improve QoL, confidence, self-management and health outcomes. Because the needs of PwPD and their caregivers are fluctuating through the different stages of the disease, initiatives should be ongoing offers, ideally with an open-door approach.

### **4.3 Practice implications**

Findings from this review emphasise the need for future interventions to be multidisciplinary, multi-sectoral and aimed at both PwPD and caregivers' needs. Most importantly, to address the ongoing needs, initiatives should be offered on a continuous basis, preferably through a PD coordinator who can facilitate a person-centred approach and support communication among agents.

#### **Declaration of interest:**

All authors declare that they have no declarations of interest.

We confirm all patient/personal identifiers that persons have been removed or disguised so that patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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Table 1. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Peer-reviewed primary studies focused on:	Systematic reviews, theses and conference papers
People diagnosed with idiopathic PD	
People with atypical PD	
Caregivers of PwPD	
Integrated care initiatives	
Studies with clear multi-sectoral collaboration	
Studies reported in:	
Catalan, Danish, English, German, Norwegian, Portuguese, Spanish, or Swedish	

Figure 1. Search results, study selection and inclusion process

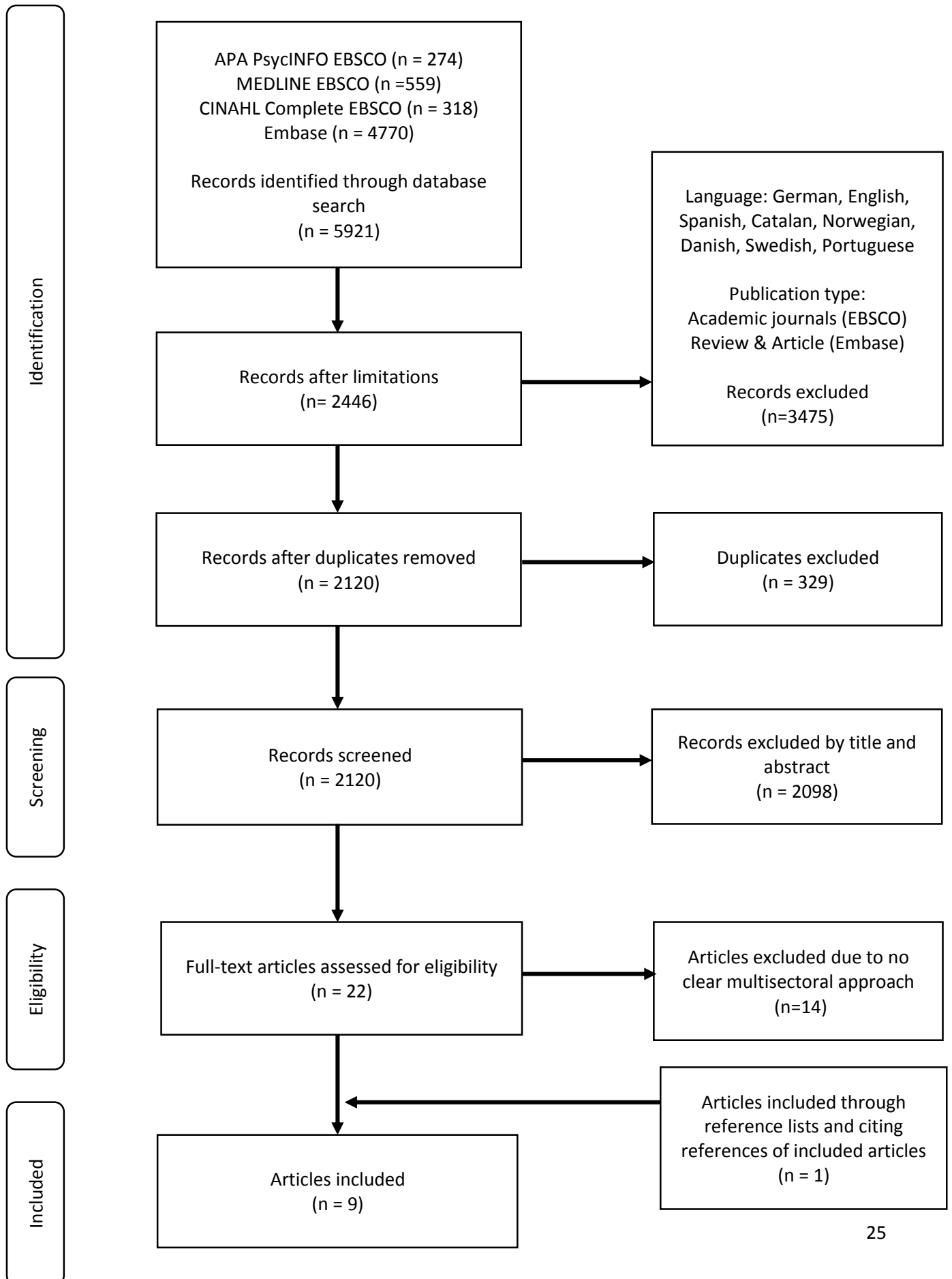


Table 2. Included articles

First author; Year of publication; Country of origin	Title	Objective	Design/Method	Population; Duration of PD; Stage of disease	Multidisciplinary care	Multi-sectoral objective
Vaughan, 2017, USA <sup>31</sup>	A Comprehensive Approach to Care in Parkinson's Disease Adds Quality to the Current Gold Standard	To describe the implementation of the <b>Comprehensive Care Clinic (CCC)</b> and to compare quality of PD care received in CCC versus usual specialist care	Design: Retrospective chart review  Method: Matched pair analysis and descriptive statistics	Population: PwPD*  PD CCC (n=29) Specialist care (n=29)  Duration of PD: y = 7, 6  Stage of disease: middle, but open to all	Specialists in sleep medicine, psychiatry, geriatrics, neuropsychology, speech and language therapy, occupational therapy, physical therapy, social services and the movement disorder programme	By crossing departmental boundaries and including multidisciplinary integration, the objective of this initiative was to improve outcomes in patient care and QoL** by making patient care more patient-centred, coordinated and timely.
Blanco, 2019, Spain <sup>30</sup>	Micro ad-hoc Health Social Networks (uHSN). Design and evaluation of a social-based solution for patient support	To contribute to the design, development, and assessment of a new concept: <b>Micro ad hoc Health Social Networks (uHSN)</b> , to create a social-based solution for supporting patients with chronic disease and to present the assessment of the final evaluation of the proposed uHSN	Design: Mixed method study  Method: Survey, data log, interviews, focus groups	Population: PwPD and people with stroke  PD association: PwPD (n=8) HCP*** (n=5)  Hospital stroke rehabilitation section: PwPD (n=6) Caregivers (n=5) HCP (n=2)  Duration of PD: Unclear  Stage of disease: Unclear	PD association: physiotherapist, speech therapist. Psychologist  Stroke: physiotherapist, computer technician	To facilitate and improve communication among HCP and patients and caregivers beyond sectoral borders.
Fleisher, 2018, USA <sup>27</sup>	Interdisciplinary Home Visits for Individuals with Advanced Parkinson's Disease and Related Disorders	To describe and evaluate the interdisciplinary <b>Home Visit Program (HVP)</b> as an initiative to identify homebound individuals at risk of loss to follow-up and deliver comprehensive care to facilitate aging in place	Design: Retrospective chart review  Method: Descriptive statistics	Population: Homebound people with advanced PD and related disorders (PD dementia, dementia with Lewy bodies and atypical Parkinsonism) (n=85)  Caregivers (n=74)  Duration of PD: Median = 9 years	Movement disorder specialist (neurologist), Movement disorders fellow, Registered nurse, Social worker (team coordinator)	To qualify individuals in eligible areas by making the needed referrals ranging from in-home physical, occupational, speech and swallowing services to supportive counselling and friendly visitor services and home-based primary care.



				Stage of disease: Median = Hoehn & Yahr stage 4, but open to all		
Fleisher, 2020, USA <sup>34</sup>	Disease severity and quality of life in homebound people with advance Parkinson disease. A pilot study	To describe retention in and satisfaction with the <b>Home Visit Program (HVP)</b> over one year; disease progression in advanced homebound individuals over time; and whether the HVP can stabilize QoL despite expected functional decline	Design: 1-year prospective cohort study  Method: Analytical statistics	Population: Homebound people with advanced PD (n=27) Caregivers (n=10)  Duration of PD: mean 10, 5 years  Stage of disease: Median = Hoehn & Yahr stage 4	Movement disorder specialist (neurologist), movement disorder fellow, registered nurse, social worker (team coordinator)	To qualify individuals in eligible areas by making the needed referrals ranging from in-home physical, occupational, speech and swallowing services to supportive counselling and friendly visitor services and home-based primary care.
Fleisher, 2020, USA <sup>32</sup>	Interdisciplinary palliative care for people with advanced Parkinson's disease: a view from the home	To describe the two iterations of the <b>Interdisciplinary home visit model (IN-HOME-PD)</b> for people with advanced PD and their care partners including two cases to illustrate the challenges and opportunities of the approach	Design: Prospective case cohort study  Method: Descriptive statistics	Population: PwPD (n=52) Caregivers (n=52)  Duration of PD: mean 15,4 years  Stage of disease: Hoehn & Yahr stage 4	Nurse Study coordinator Social worker (telemedicine for visits 2-4) Movement disorder specialist (neurologist) (telemedicine)	Through professional integration and coordinated care, this multi-sectoral approach sought to deliver and increase access to care by extending team-based medical treatment, psychosocial support and health education; enhance safety; reduce caregiver strength; and empower PwPD and caregivers to achieve the best end-of-life QoL.
Muñoz, 2020, Colombia <sup>28</sup>	Saturdays-in- Motion: Education and Empowerment through an Interdisciplinary Team Approach for Parkinson's Disease in Cali-Colombia	To document the experience of patients, caregivers and experts in a community approach ( <b>Saturdays in Motion, SIM</b> ) as an innovative model in a middle-income country	Design: Mixed-method study  Method: Surveys and questionnaires	Population: PwPD (n=48) Caregivers (n=21) HCP (n=4)  Duration of PD: median 4 years  Stage of disease: N/A	Physicians (neurologist, neurology resident, GP), physical therapy expert, neuropsychologist, volunteers (undergraduates and master's students from medicine, engineering and design)	To strengthen the bonds between PwPD, caregivers and clinical experts.
Navarta- Sánchez, 2020, Spain <sup>35</sup>	Evaluation of a psychoeducational intervention	To evaluate the short and long-term effects of <b>a</b>	Design:	Population:  PwPD (n=140)	General practitioner, neurologist, nurse, social worker, psychologist	To strengthen QoL*, psychosocial adjustment and coping in PwPD and

	compared with education in people with Parkinson's disease and their informal caregivers: a quasi-experimental study	<b>psychoeducational intervention compared with an education programme</b> in strengthening QoL*, psychosocial adjustment, and coping in people with Parkinson's disease and their informal caregivers	A quasi-experimental study  Method: Analytic statistics	Caregivers (n=127)  Duration of PD Experimental group mean 5,8, control group 7,8 (p=0,033)  Stage of disease: Experimental group and control group: All stages represented, but most were in stage I, II, III		their caregivers, through a multidisciplinary team approach involving multiple sectors of care.
Kessler, 2020, Canada <sup>29</sup>	The Integrated Parkinson's disease Care Network (IPCN): Qualitative evaluation of a new approach to care for Parkinson's disease.	To evaluate the acceptability of <b>The Integrated Parkinson's disease Care Network (IPCN)</b> from the perspectives of persons with Parkinson's disease (PD), corresponding care partners and healthcare providers, including identification of important components and areas for improvement	Design: Descriptive qualitative approach  Method: Semi-structured interviews and focus groups using conventional content analysis	Population: PwPD (n=32) Caregivers (n=7) Healthcare professionals (n=7)  Duration;stage of disease: Newly diagnosed PwPD (< 1 year, n=4) People with advanced PD (> 8 year or Hoehn and Yahr score≥3, n=11)	Nurse specialised in PD, Home-based interventions (home care medical/personal assistance, meal delivery services), Community-based services (community senior services, social services), long-term care/respite, Allied health interventions ( physiotherapy, occupational therapy, speech-language pathology, assessment for adaptive equipment, emergency alert services), Medical interventions (mental health services, medical specialist), other services (self-help/group therapy, transportation services, massage therapy)	To break down silos in the health care system and increase communication and accessibility to existing care resources of interest to PwPD and caregivers
Mestre, 2021, Canada <sup>33</sup>	Pilot evaluation of a Pragmatic Network for Integrated Care and Self-management in Parkinson's Disease	To evaluate the implementation and impact of a pragmatic network for PD care, <b>The Integrated Parkinson Care Network (IPCN)</b>	Design: 6 months, pre-post design, phase 2 study of complex interventions;  Method: Descriptive statistics and repeated linear regression analysis +	Population: PwPD < 1year (n=25) People with advanced PD (n=73) Caregivers (PD < 1-year n= 18, Advanced PD n=56)  Duration of PD: Mean 9.6 ±7.3 years  Stage of disease: Newly diagnosed PwPD (< 1 year, n=25)	See above	See above

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stratified  
analysis

People with advanced PD (> 8  
year or Hoehn and Yahr  
score $\geq$ 3, n=73)

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\*PwPD = People with Parkinson's disease

\*\*QoL = Quality of life

\*\*\* HCP = Health care professionals

Table 3. Characteristics of the included initiatives, outcomes and findings

First author; Year of publication; Country of origin	Initiative	Duration/setting	Content-specific characteristics	Outcome	Findings
Vaughan, 2017, USA <sup>31</sup>	Comprehensive Care Clinic (CCC)	Duration: 2-day evaluation with a one-year follow-up  Setting: Comprehensive care visit/university- based program	Assessment of motor and non-motor symptoms leading to the development of a person-centered comprehensive care plan	PwPD* in the CCC program received mean 9.9 of 10 AAN** assessments versus patients seen by specialists, who received mean 4.5, p<0.001.  CCC PwPD were more likely to be advised to adjust PD medications at baseline visits (p 0.05). No difference in advice at follow-up.  Adjustment of antidepressants in statistically significantly more CCC PwPD (p<0.001).  UPDRS*** scores improved from baseline to follow-up in both groups; no statistical between- group difference: (p 0.50).	CCC PwPD were more likely to receive adjustments in PD medication and antidepressants and received more AAN assessments than the control group, interpreted as higher quality of care. UPDRS scores improved from baseline to follow-up in both groups.
Blanco, 2019, Spain <sup>30</sup>	Micro ad- hoc Health Social Networks (uHSN)	Duration: 6-months experimental pilot project  Setting: Online platform	To create a social-based solution for supporting patients with chronic disease. Online learning platform allows multidisciplinary healthcare professionals, patients and caregivers access to educational materials, to information exchange, data registration and a treatment module, which allows the definition and assignment of costume therapy	Quality of service enhancement: 100 % of all users acknowledged that the uHSN enhanced personalized assistance and care.  45 % of patients and 40 % of professionals thought that the process to learn to use uHSN could be improved upon.  80 % of all users confirmed global positive outcomes of uHSN utility in professional management.  90 % of patients and professionals agreed that use of uHSN enabled new communication channels between patients and health professionals and improvement in empathy, reciprocity and affective companionship for assistance and disease care. Patient medication management improved in 93 % of participants.	The users found outcomes to the uHSN globally positive; they found it enhanced personal assistance and care and improved patient medication management. Patient and professionals agreed that uHSN enabled new communication channels and improvement in empathy, reciprocity and affective companionship between them. However, many found that the learning process to use the uHSN could be improved upon.

Fleisher, 2018, USA <sup>27</sup>	Home Visit Program (HVP)	Duration: Up to 4 visits per year (median 3) with follow-up phone calls 2 weeks after each visit  Setting: In-home visits	A comprehensive person-centred assessment and plan based on a physical examination, medication reconciliation and assessment of psychosocial needs and home safety	Satisfaction with intervention: PwPD (n = 41 answered): median score (0-100): 96,3  Caregivers (number of respondents not reported): median score (0-100): 98,1	Satisfaction with participation in the intervention was very high among both PwPD and their caregivers.
Fleisher, 2020, USA <sup>34</sup>	Home Visit Program (HVP)	Duration: 4 visits per year with follow-up phone calls 2 weeks after each visit  Setting: In home-visits	A comprehensive person-centred assessment and plan based on a physical examination, medication reconciliation and assessment of psychosocial needs and home safety	Satisfaction with the intervention after 4 visits, median score (0-100): PwPD: 97 Caregivers 98  Statistically significant changes in outcomes over 1 year: Mean UPDRS mentation/behaviour/depression score worsened from 2,9 to 4,3 Motor scores worsened from 34,4 to 42,5 Mean UPDRS total worsened from 60,5 to 72,3 Despite the abovementioned disease progression, no significant changes in any QoL**** domains were found (p= 0,19-0,95)  Caregiver strain: Significant increase in strain from 17,2 (mild) to 23,2 (moderate) (p= 0,04)  Health utilization: Despite disease progression and isolation, health utilization remained the same (p= 0,15) and none were institutionalised during the study.	Satisfaction with participation in the intervention was very high among both PwPD and caregivers. HVP seems to stabilize QoL and hinder additional use of health utilisation, despite disease progression and isolation
Fleisher, 2020, USA <sup>32</sup>	Interdisciplinary Home Visits for Parkinson's disease (IN-HOME PD)	Duration: 4 visits per year, with follow-up phone calls 2-8 weeks post-visit  Setting: In home visits with participation by some professionals through tele health	A comprehensive person-centred assessment and plan based on a physical examination, medication reconciliation and assessment of psychosocial needs and home safety	N/A	The pilot data suggest high satisfaction and stabilization of patient QoL* despite disease progression. Ongoing work, illustrated by the two case studies, highlights the importance of medication reconciliation, home safety assessments, and appropriate monitoring and treatment of OH.

Muñoz, 2020, Colombia <sup>28</sup>	Saturdays-in-motion (SIM)	Duration: One four-hour session per month.  Setting: A private high complexity university hospital	The initiative sought to improve QoL in PwPD and caregivers through education, cognitive and physical rehabilitation, leisure activities, strengthening of bonds between PwPD, caregivers and clinical experts, enhancing home management, peer-support and mitigation for caregiver burnout.	95.8 % of PwPD considered that SIM improved their QoL. 87,5 % of PwPD found that SIM increased their awareness of PD symptoms, 79,1 % that SIM increased their awareness of PD itself.	The tested intervention may improve the QoL of PwPD.  Useful aspects of Saturday in Motion pointed out by caregivers included: improved knowledge and understanding of PD, becoming able to provide better information to physician, to recognise new symptoms, and to know symptoms that can be managed at home.
Navarta-Sánchez, 2020, Spain <sup>35</sup>	A psycho-educational intervention	One 90 minutes group session per week for 9 weeks  Setting: primary care centers	Education program consisting of: Information about PD, healthy lifestyle and community resources,  Psychoeducational dimension, consisting of four sessions about the psychosocial adaptation to PD and coping skills; benefits of practicing positive self-esteem; relaxation technics and advantages of looking for information, living in the present and partake in activities.	No improvement in coping skills among PwPD in either group, p 0.471, and there were no significant between group differences, p 0.998.  Caregivers in both groups improved their coping skills at T1, p 0.004; This was not maintained at T2 and no significant between group differences were found p 0.781.  PwPD in both groups significantly improved their QoL from baseline to T1. p<0.001, it was not maintained at T2. No between group difference at any point of time, p 0.554.  No caregivers in either group improved their QoL at any point of time  Both groups of PwPD improved on psychosocial adjustment from baseline to T1, p<0.01; it was not maintained at T2. No between group differences at any time.  Same conclusion concerning the caregivers	The intervention was not superior to the control condition. PwPD in both groups improved QoL* and psychosocial adjustment but had lost their improvements again at long-term follow-up.  The same conclusion applies to caregivers.  No groups of PwPD improved their coping skills whereas the caregivers in both groups had improved their coping skills at T1 but had lost them again at T2.
Kessler, 2020, Canada <sup>29</sup>	The Integrated Parkinson's Care Network (IPCN)	Duration: 6 months, entailing an initial 90 minutes visit, a 1-month telephone call to review the personal care plan, a 3-	Patient education, which entailed educational tip sheets based on available evidence and guidelines for care needs in PD; 2) Self-management	N/A (qualitative study)	The support offered by the CCI***** is tailored to individual needs providing confidence and comfort, and as providing the linkage to services and resources  PwPD and caregivers appreciated the new knowledge provided by the CCI, which was

		months optional visit and a 6-months close-up visit to evaluate the degree of completion of the personal care path.	Setting: clinic	support based on the 5 A's Approach (assess, advise, agree, assist, arrange) and 3) Care navigation, based on the identification and development of existing healthcare resources relevant for PD care. A personalised care plan was conducted, through shared decision-making, which created the basis for facilitating health care navigation for resources selected by the patient.	delivered in a sensitive and positive way. However, some felt that knowledge provided could be more individualised and holistic, also including mental health education. The identification of goals, using the electronic self-report assessment of PD symptoms, and subsequent formulating of plans were perceived collaborative. However, some newly diagnosed PwPD felt distressed by the awareness of potential future problems. The CCI support was integral to goal achievement, and to advocate and make follow-up on in goals involving referrals in order to facilitate the process. Barriers to goal achievements were waitlists and costs to access resources, in addition some resources did not match their need and abilities.
Mestre, 2021, Canada <sup>33</sup>	The Integrated Parkinson's disease Care Network (IPCN)	See above	See above	PwPD improved their perception of support for dimensions of chronic care and for self-management; the advanced group maintained the improvements at 3 months but not the newly diagnosed group.  76,6 % of participants were very satisfied with the IPCN experience 74,5 % reported a significant improvement in their condition  The PwPD significantly improved their QoL, the change pertained to the advanced group but not to the newly diagnosed group.	HCP*'s perceived encouragement, education and positivity as important to promote self-management. However, the perceived readiness for self-management differed. PwPD attending the IPCN seemed more emotionally prepared than PwPD not attending the IPCN. Some proactive PwPD, who already sought information by themselves, wanted more feedback from the CCI. While some felt empowered to manage their own health after the IPCN, others were not ready for the support to end.  General satisfaction was high among participants, and many reported a significant improvement in their condition. People with advanced PD significantly improved their QoL, they improved their perception of support and maintained this over three months.  People with newly diagnosed PD did not significantly improve their QoL, they improved their perception of support, but did not maintain improvement at three months follow-up.

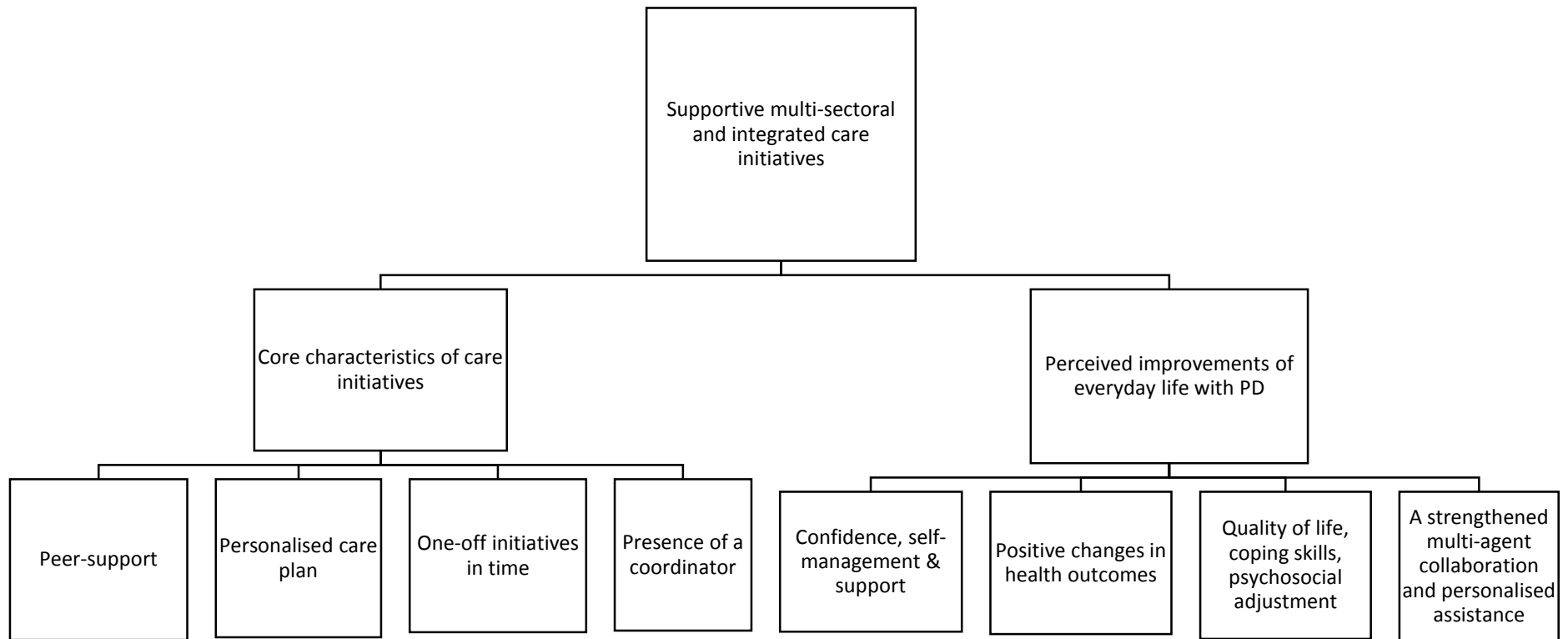
\*PwPD = People with Parkinson's disease  
\*\*AAN = American Academy of Neurology 2009 Quality Indicators  
\*\*\*UPDRS= Unified Parkinson's Disease Rating Scale  
\*\*\*\*QoL = Quality of life  
\*\*\*\*\* CCI = clinical care integrator



Table 4. Review matrix of characteristics of the multi-sectoral integrated care initiatives and perceived improvements of everyday life for PwPD and caregivers

	Core characteristics of care initiatives				Improvement of everyday life with PD			
	Peer-support	Personalised care plan	One-off initiatives limited in time	Presence of a coordinator	Confidence, self-management & support	Positive changes in health outcomes	Quality of life, coping skills & psychosocial adjustment	A strengthened multi-agent collaboration and personalised assistance
Vaughan, 2017, USA <sup>31</sup>		x	x	x		x		x
Blanco, 2019, Spain <sup>30</sup>	x		x			x		x
Fleisher, 2018, USA <sup>27</sup>		x	x	x	x			
Fleisher, 2020, USA <sup>34</sup>		x	x	x		x	x	
Fleisher, 2020, USA <sup>32</sup>		x	x	x			x	x
Muñoz, 2020, Colombia <sup>28</sup>	x	x	x		x	x	x	x
Kessler, 2020, Canada <sup>29</sup>	x	x	x	x	x			
Mestre, 2021, Canada <sup>33</sup>		x	x	x	x		x	
Navarta-Sánchez, 2020, Spain <sup>35</sup>	x		x				x	

Figure 2: Themes and corresponding subthemes



### **Declaration of interest**

We state that the article has not been submitted for publication in another journal or elsewhere. Furthermore, there are no financial or any relationships that could lead to declaration of interest in relation to this manuscript. Though, one article in the review has been written by one of the co-authors, we believe that the study adds value to the objective of this present study.

## Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
<b>TITLE</b>			
Title	1	Identify the report as a scoping review.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	2
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	3
<b>METHODS</b>			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	No
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	4
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	4
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix B
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	4, Table 1
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	5
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	6
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	5

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
<b>RESULTS</b>			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Table 2, 3, 4
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	6
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	5-11
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	5-11
<b>DISCUSSION</b>			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	11-13
Limitations	20	Discuss the limitations of the scoping review process.	13
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	14
<b>FUNDING</b>			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	14

JB1 = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

\* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: 10.7326/M18-0850.



## Appendix A. Description of the electronic search in EBSCO (MEDLINE, Cinahl Complete &amp; APAPsycInfo)

Population	Concept (intervention)	Context (outcome)
"Parkinson disease" OR "Parkinsonian disorders" OR parkinson* OR parkinsonism OR "parkinson's disease"	"adaptation" OR "quality of life" OR "adaptation, psychological" OR "coping" OR "health behavior" OR "self care" OR "self-management" OR "health behaviour" OR "self-care" OR "coping behavior"	"patient education" OR "patient care plan*" OR "continuity of patient care" OR "practice guidelines" OR "patient discharge" OR "critical path*" OR "models organizational" OR "patient admission" OR ( "referral and consultation" ) OR "regional medical programs" OR "delivery of health care, integrated" OR "care path*" OR "intersectoral collaboration" OR "models organisational" OR "health services research" OR multisector* OR "multi- sector*" OR intersector* OR "inter-sector*" OR ( "health and welfare plan*" ) OR "health services access*" OR "interinstitutional relations" OR "discharge plan*" OR "treatment plan*" OR "patient care" OR "continuum of care" OR "client education" OR "hospital discharge" OR "patient referral" OR "integrated services" OR "integrated health care system*" OR "health care quality" OR "quality assurance health care" OR "health care service*" OR "health service*" OR "public relation*" OR "transfer discharge" OR "clinical guideline*" OR "clinical path*" OR "health care plan*" OR "health care delivery"

Limitations

Publication Type: Academic Journals

Language: Spanish, English, Spanish; Castilian, Portuguese, Norwegian, Danish, Swedish, German

### **Sample CRediT author statement**

**Vester LB:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Writing-original draft, Visualization **Haahr A:** Conceptualization, Methodology, Writing- Original draft, Supervision, Project administration, Funding acquisition. **Nielsen TL:** Conceptualization, Validation, Writing – Review & Editing, Supervision. **Bartolomeu PS:** Investigation, Writing – Review & Editing. **Portillo MC:** Writing – Review & Editing, Supervision, Project administration, Funding acquisition.