Supplementary Tables 1-3.

Supplementary Table 1a. Interventions: group-based patient education programs – Study characteristics and relevant findings

| **First author, year** | **Study aims and *review specific aimsa*** | **Design** | **Setting** | **Sample characteristics** | **Intervention** | **Patient outcomes** | **Relevant findingsf** |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **A’Campo,2010 [1]&A'Campo,2012 [2]** | To evaluate the effectiveness of the Patient Education Program (PEPP) and to search for treatment effect modifiers. | * RCT
* Intervention (n=32) vs control (n=29) group
* Pre-questionnaire
* Post-questionnaire directly after the intervention.
 | N=61, from one academic medical center in the Netherlands. | **Ageb****(years, M** ±**SE)** | 65.5 ± 8.9 | The PEPP = Patient Education Program Parkinson.The program consisted of eight 90-minute sessions aimed at understanding, managing, and coping with PD. | * Patient-reported QoL (PDQ-39 SI)
* Patient-reported mood (100-point VAS)
* Patient reported psychosocial problems and need for help (BELA-P-k).
* Self-rating Depression Scale (SDS).
 | * PEPP participants’ post-intervention QoL was improved *(M change = 3.07),* whereas control patients’ QoL worsened *(M change= -1.79; p<.05). Authors used reversed scoring.* No modifiers were found.
* PEPP participants' mood significantly improved temporarilyafter each session *(p= .001)* and was not compared with the control group.
* Other outcomes NS.
 |
| **Gender****(% female)** | 48 |
| **Hoehn & Yahr (H&Y)c** | 1(n=18), 2&3(n=38), 4&5(n=4) |
| **Disease durationd****(years, M** ±**SE)** | 6.0 ± 5.3 |
| **Cognitive functioninge****(MMSE)** | 27.4 ± 3.4 |
| **A’Campo,2011 [3]** | To assess patient outcomes of the Patient Education Program (PEPP) in a new sample in daily clinical practice, compared to the results of a previous RCT (A’Campo 2010) and at 6-month follow-up. | * Single group
* Pre- questionnaire
* Post-questionnaire directly after the intervention and 6 months later

Questionnaire data were compared with data from an RTC. | N=42, from one academic medical center in the Netherlands. | **Ageb****(years, M** ±**SE)** | 68 ± 11 | The PEPP program consisted of eight 90-minute sessions aimed at understanding, managing, and coping with PD. | * Patient-reported QoL (PDQ-39 SI).
 | There was a stronger increase in patients’ QoL pre to post intervention in clinical practice compared to the RCT group *(M change = 3.8 vs. 3.1, p<.05*). *Authors used reversed scoring.* Patients’ QoL returned to baseline level after 6 months. |
| **Gender****(% female)** | 43 |
| **H&Yc** | 1(n=21), 2&3(n=30), 4&5(n=4) |
| **Disease durationd****(years, M** ±**SE)** | 8.6 ± 6.7 |
| **Cognitive functioninge****(MMSE)** | 27.9 ± 1.8 |
| **Canivet,2015 [4]** | To assess the impact of an education program on patients' QoL, and motor and psychological function compared to traditional care in PD patients. | * RCT
* Intervention (n=60) vs control (n=60) group
* Pre-questionnaire
* Post-questionnaire directly after the full intervention.
 | N=120, from one academic medical center in France. | **Ageb****(years, M** ±**SE)** | 62.1 ± 7.1 | Education program with one year duration. Consisted of one 90-minute individual tailored session and 3 quarterly 4-hour group sessions (10p max). | * Patient-reported QoL (PDQ-39)
* Patient-reported general QoL (SF-36)
* Patients’ experiences of non-motor symptoms (UPDRS-I)
* Patient-reported ADL (UPDRS-II)
* Clinically measured motor performance (UPDRS-III)
* Total score of the UPDRS
* Patient-reported anxiety and depression (HADS).
 | * There were significant improvements pre to post intervention compared to the control group in patients’ total UPDRS (*M change* = -1.69 vs. 3.46), ADL (-0.96 vs. 1.37) and non-motor aspects (-0.40 vs. 0.44); all p-values <.01).
* Other outcomes NS
 |
| **Gender****(% female)** | 41 |
| **H&Yc** | 1(n=23), 2(n=71), 3(n=25) |
| **Disease durationd****(years, M** ±**SE)** | 4.9 ± 4.3 |
| **Cognitive functioninge** | NR |
| **Chlond, 2016 [5]** | To re-evaluate the effectiveness of the Patient Education Program (PEPP) and to assess the sustainability of the effect. | * RCT
* Intervention (n=38) vs control (n=29) group
* Pre-questionnaire
* Post-questionnaire directly after the intervention and 3 months later.
 | N=67, from medical centers (N= NR) in Germany. | **Ageb****(years, M** ±**SE)** | 63.2 ± 10.6 | The PEPP program consisted of eight 90-minute sessions aimed at understanding, managing, and coping with PD. | * Patient-reported QoL (PDQ-39 SI)
* Patient-reported general QoL (EQ-5D)
* Patient-reported coping behavior (FKV-LIS-SE)
* Report of psychosocial problems and need for help (BELA-P-k).
* Patient-reported sense of coherence (SOC-29)
* Patient-reported mood (HADS-D)
* Patient-reported optimistic expectations regarding oneself (GSE).
 | * There were significant increases pre to post intervention in patients’ disease-specific QoL directly after PEPP and 3 months later *(M change= 4.26 and 3.85, resp.),* whereas QoL of control patients worsened *(M change= -3.7 and -3.4, resp.; p<.01).*
* There was an increase pre to post intervention in active problem-orientated coping behavior compared to the control group *(M change: 3.69 vs. 3.18, p<.05)*
* Other outcomes: NS.
 |
| **Gender****(% female)** | 39 |
| **H&Yc** | Mean 2.2 ± 0.7 |
| **Disease durationd****(years, M** ±**SE)** | 7.2 ± 5.3 |
| **Cognitive functioninge** | NR |
| **Derollez, 2021 [6]** | To assess change in QoL after participating in a patient education program called EduPark and to identify predictive factors for a QoL change.*To assess patients' preferences for specific information in workshops and the impact of EduPark participation on their QoL.* | Comparison between 2 non-randomized groups, both undergoing the intervention: 1. Out-patient clinic participants (n=120)
2. Digital participants (n=85)

*(n=24 participated in both groups)** Pre-questionnaire
* Post-questionnaire directly after the intervention.
 | N=181, from one academic medical center in France. | **Ageb****(years, M** ±**SE)** | 62.9 ± 8.2 | Patient education program, based on EduPark (Macht, 2007, Simons 2006)Participation in 1-10 of 10 educational workshops, depending on patients’ needs. Workshops were either attended at the out-patient clinic or digitally from home. | * Patient-reported QoL (PDQ-8)
* Patient-reported psychosocial section of the Scales for Outcomes in Parkinson’s disease (SCOPA-PS).
 | * Significant increase pre to post intervention in patients’ QoL in both groups (*M change* = -3.8, p<.001). Digital participants’ QoL also significantly increased pre to post intervention, whereas the hospital group only showed a non-significant trend.
* Reduction of psychosocial disease impact pre- to post intervention in both groups (*M change* = -0.8, p<.001).
 |
| **Gender****(% female)** | 47 |
| **H&Yc** | 1(n=62), 2(n=86), 3(n=25), 4(n=5), 5(n=1) |
| **Disease durationd****(years, M** ±**SE)** | 9.1 ± 5.3 |
| **Cognitive Functioninge****(MMSE/****MOCA)** | No(n=79), MCI(n=16), moderate/severe impairment(n=8)  |
| **Guo, 2009 [7]** | To evaluate the effect of a group education program with personal rehabilitation for PD. | * RCT
* Intervention (n=23) vs control (n=21) group
* Pre-questionnaire
* Post-questionnaire 8 weeks after the intervention.
 | N=44, from one academic medical center in China. | **Ageb****(years, M** ±**SE)** | 64.6 ± 6.8 | Three 45-minute lectures, focused on the day-to-day management of PD. Moreover, relevant information was published on an exclusive website. | * Patient-reported QoL (PDQ-39)
* Patient-reported ADL (UPDRS II)
* Clinically measured motor performance (UPDRS-III)
* Self-rated ADL (SEADL)
* Self-rating Depression scale (SDS)
* Patient-reported mood (100-point VAS).
 | * There were significant improvements pre to (8 weeks) post intervention, in the intervention vs. control group in patients’ QoL *(M change = -14.6 vs. -0.1*), ADL *(-5.0 vs 0.4),* motor performance *(-12.8 vs. -1.1)* and mood *(20.3 vs. 0.2); all p-values <.001.*
* Other outcomes: NS
 |
| **Gender****(% female)** | NR |
| **H&Yc** | Mean H&Y 2.2 ± 0.5  |
| **Disease durationd****(years, M** ±**SE)** | 5.4 ± 4.5 |
| **Cognitive functioninge****(MMSE)** | 28.2 ± 1.4 |
| **Hellqvist, 2018 [8]** | To identify valuable topics within the National Parkinson School (NPS) according to patients. *To assess patients’ evaluation regarding the timing of information and participating in the NPS.* | * Single group
* Qualitative analysis on transcripts of the audio-record of the last session of the NPS, which included a reflection on the educational program.
* Inductive, thematic analysis.
 | N=25, from 5 out-patient geriatric and neurology clinics in Sweden. | **Ageb****(years, M** ±**SE)** | NR | An education program inspired by PEPP. The program consisted of seven sessions aimed at understanding, managing, and coping with PD. | * Evaluation of participating in a group
* Evaluation of the timing of the provided information.
 | * Patients appreciated the fruitful exchange of knowledge and experiences between group participants, although they also realized that their symptoms varied considerably.
* Patients thought that the provided information would be most useful within one year after diagnosis.
 |
| **Gender****(% female)** | 44 |
| **H&Yc** | n=3), 2(n=13), 3(n=9). |
| **Disease durationd****(years, M ±SE)** | <13  |
| **Cognitive functioninge** | NR |
| **Macht, 2007 [9]** | To describe patient outcomes and evaluation of the EduPark education program. | * Single group
* Pre- questionnaires
* Post-questionnaires directly after each session and after the intervention.
 | N=151, from the edupark consortium in seven European countries.  | **Ageb****(years, M ±SE)** | 64.4 ± 9.2 | EduPark education program: 8 x 90-minute live sessions, provided by expect clinicians, on topics which aim to empower patients in living with PD. | * Patients’ evaluation of the provided information
* Patient-reported Mood (100-point mood VAS)
* Patient-reported QoL (PDQ-39)
* Patient-reported psychosocial problems and need for help (BELA-P-k).
* Self-rating Depression Scale (SDS).
 | * Patients evaluated the provided information mainly positive, with 53% stating that their understanding of PD had improved. The majority of patients reported having received new (77%) and helpful (82%) information. 34% would have liked to receive more information.
* Patients’ mood increased temporarily over each education session.
* After PEP, patients reported decreased psychosocial problems and need for psychosocial help compared to before PEP *(mean change: - 5.7, p<.001).*
* Other outcomes: NS.
 |
| **Gender****(% female)** | 40 |
| **H&Yc** | Mean 2.0 ± 0.8 |
| **Disease durationd****(years, M ±SE)** | NR |
| **Cognitive functioninge****(MMSE)** | 28.0 ± 2.1 |
| **Oki, 2019 [10]**  | To determine the effect of an educational program on patients’ QoL.  | * Single group
* Pre- questionnaires and assessments
* Post-questionnaires and assessments directly after the intervention.
 | N=22, setting NR | **Ageb****(years, M ±SE)** | 71.3 ± 8.5 | 1-6 of six monthly one-hour lectures on PD with PowerPoint and handouts.  | * Patients’ evaluation of mentation, behavior, and mood (UPDRS-I)
* Patient-reported ADL (UPDRS-II)
* Clinically measured motor performance (UPDRS-III)
* Patient-reported general QoL (SF-36v2).
 | * Patients' motor performance was worse after the intervention compared to before. (*M chang*e = 2.0, no significance testing reported).
* Other outcomes: NS.
 |
| **Gender****(% female)** | 46 |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | 7.6 ± 6.0 |
| **Cognitive functioninge** | NR |
| **Simons, 2006 [11]** | To describe patient outcomes and evaluation of the EduPark education program. | * Single group
* Pre- questionnaires
* Post-questionnaires directly after each session and after the intervention.
 | N=16, from the EduPark consortium in the UK. | **Ageb****(years, M ±SE)** | NR | EduPark education program: 8 x 90-minute live sessions, provided by expect clinicians, on topics which aim to empower patients in living with PD. | * Patients’ evaluation of the provided information
* Patient-reported Mood (100-point mood VAS)
* Patient-reported QoL (PDQ-39)
* Patient-reported psychosocial problems and need for help (BELA-P-k).
* Self-rating Depression Scale (SDS).
 | * All patients stated that they received helpful information, that their understanding of PD had improved and that the group atmosphere was comfortable.
* Patients’ mood increased temporarily over each education session *(M score: 11.2, p<.05.)*
* Other outcomes: NS
 |
| **Gender****(% female)** | NR |
| **H&Yc** | Range 1-4 |
| **Disease durationd****(years, M ±SE)** | NR |
| **Cognitive functioninge****(MMSE)** | 29.4 ± 0.9 |
| **Spurthi, 2023 [12]** | To compare the effectiveness of three different oral health education interventions on plaque removal | * 3 randomized groups received the same information in different formats
* Pre- questionnaires
* Post-questionnaires 1, 2, and 3 months after intervention
* Clinical measurements at 3 months after intervention
 | N=63, (n=21 in each group), from one medical center in India. | **Ageb****(years, M ±SE)** | 54 (12.3) | 20 minute education sessions on oral health. Three formats:1) lectures with written texts;2) presentations in pictorial form;3) visual and interactive demonstrations | * Tested knowledge (%)
* Dental plaque index (PI)
* Patient hygiene performance index (PHPI)
 | * Patients’ knowledge decreased for all groups over time (p.<001).
* Patients’ PI was decreased for all groups after 3 months (F=11.54, p<.001)
* Patients receiving pictorial information had a higher knowledge (M difference in change= 8.8%, p<.05 and a lower PI than patients from group 1 and 3.

Other outcomes NS |
| **Gender****(% female)** | 30 |
| **H&Yc** | <3 |
| **Disease durationd****(% <6 years)** | 79 |
| **Cognitive functioninge (MOcA or MSSE)** | >26 |

*a, b, c, d, e, f and abbreviations: see caption below Supplementary Table 3.*

Supplementary Table 1b. Interventions: individual information provision - Study characteristics and relevant findings

| **First author, year** | **Study aims and *review specific aimsa*** | **Design** | **Setting** | **Sample characteristics** | **Intervention** | **Patient outcomes** | **Relevant findingsf** |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Afshari, 2024 [13]** | To test the feasibility and preliminary efficacy of a virtual home-based fall prevention program.*To assess patients’ compliance with therapists’ safety recommendations* | * Single group
* Post intervention collaborative rates of therapists and patients at 10 weeks and 6 months after intervention onset.
 | N=15, from one medical center in the USA. | **Ageb****years, (median, IQR)** | 67 (64-73) | An occupational therapist provided individualized recommendations during two bi-weekly virtual home-safety tours. | * Rate of compliance with recommendations
 | After 10 weeks, 87% of recommendations provided were met, while 9% were partly met and 2% were not met at all. After 4 months, 91% of recommendations were met, while 9% were partly met.  |
| **Gender****(% female)** | 5 (33) |
| **H&Yc** | 3 (n=8, 53%) 4( n=7, 47%)  |
| **Disease duration d****(years, median, IQR)** | 8 (5-8) |
| **Cognitive functioninge (MOcA) (median, IQR)** | 25 (21-27) |
| **Brown, 2022 [14]** | To design a platform (PD-BRIDGE) that visualizes both data from the Electronic Health Record and patient outcomes, and to evaluate user experiences. *To identify patient preferences of visualized data within a platform to support clinical information and medical decision-making and to evaluate patient report of their user experience*.  | * Single group
* Pre- questionnaires
* Post-questionnaires directly after the intervention.
 | N=17, in a medical encounter in an outpatient neurology academic medical center in the VS. | **Ageb****(years, M ±SE)** | 66 ± 11 | PD-BRIGDE is a dashboard that displays data visualization modules in the Electronic Health Record to be easily reviewed by clinicians and patients during consultations. | * Patient report of the helpfulness of PD-BRDIGE
* Patient report of comfort with the implementation and perceived security of the platform.
 | * Patients reported that the PD-BRIDGE was helpful overall. 83% felt that it facilitated communication with their clinician, and 65% reported that it helped them understand their disease trajectory and clinician recommendations.
 |
| **Gender****(% female)** | 35% |
| **H&Y** | NR |
| **Disease durationd****(years, M ±SE)** | NR |
| **Cognitive functioninge****(MMSE)** | NR |
| **Cook, 2023 [15]** | To compare patients’ pre- and post-genetic test knowledge of PD genetics and satisfaction withgenetic counseling between providers. | * Two randomized groups (local vs. centralized), both receiving genetic counseling.
* One group received genetic counseling from local clinicians with limited experience, the other remotely from genetic counselors with extensive experience
* Pre- questionnaires
* Post questionnaires, four weeks after the intervention.
 | N=525, from PD foundation centers of excellence in the USA. | **Ageb****(years, M ±SE)** | 63.9±98) | Genetic test disclosure and genetic counseling according to a pre-defined counseling outline which listed consultation components.  | * Satisfaction with genetic counseling
* Knowledge of genetic testing
* Psychological impact of genetic testing (FACToR)
 | * More patients were satisfied with genetic counseling received from local clinicians than from remote genetic counselors (*93% vs. 86%. p=.05*)
* Other outcomes: NS.
 |
| **Gender****(% female)** | 41% |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | 4.9(4.8) |
| **Cognitive functioninge****(MOcA)** | ≥24 |
| **Dinkelbach, 2017 [16]**  | To evaluate the effectiveness of the combination of an outpatient Deep brain Stimulation (DBS) screening tool with educational material. | * Single group
* Post- intervention questionnaire within 16 months after initial visit.
 | N=264, Potential DBS candidates from different medical centers in Germany, who did (n=114) or did not (n=150) consent with further diagnostic assessment regarding DBS. | **Median Ageb****(years, M ±SE)** | 64, IQR 53-70 | A comprehensive information booklet, developed based upon patients' doubts and expectations regarding DBS. Additionally, a 4-minute film on DVD, illustrating the DBS procedure.  | * Patient-reported evaluation of the informational material.
 | * The consenting group evaluated the material more often as helpful (90%) than the non-consenting group (69%, p<.001).
* The consent group was more often informed regarding motor improvement, quality of life, side effects of medication, optimal time frame and evidence of DBS, compared to the non-consent group.
 |
| **Gender****(% female)** | 33 |
| **Median H&Yc** | 3.0, IQR 2-3 |
| **Median disease durationd****(years, M ±SE)** | 9, IQR 5-12 |
| **Cognitive functioninge****(MMSE)** | NR |
| **Grosset, 2007 [17]**  | To test the effect of education regarding the continuous dopaminergic theory on the timing of medication ingestion. | * RCT
* Intervention (n=33) vs control (n=36) group
* Pre-test and questionnaires
* Post-tests and questionnaires, after 3 months of intervention usage.
 | N=69, from a regional movement disorder clinic in the UK. | **Ageb****(years, M ±SE)** | 71 ± 9 | Verbal and written information on the continuous dopaminergic theory. | * Patient-reported QoL (PDQ-39)
* Timing adherence, i.e., the percentage of doses taken at the correct time interval, measured via electronically monitoring pill bottles (MEMS).
* Patient-reported motor performance (UPDRS-III).
 | * There was a median difference in timing adherence pre to post intervention between the two groups of 23.1% in favor of the intervention group (p<.001).
* Other outcomes: NS.
 |
| **Gender****(% female)** | 36 |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | NR |
| **Cognitive functioninge****(MoCA)** | 25.6 ± 3.8 |
| **Helmers, 2021 [18]**  | To examine patients’ satisfaction with and feasibility of tablet-based education modules.*To assess patients' pre- and post-module knowledge test scores.* | * Single group
* Pre-tests
* Post-tests, directly after the intervention.
 | N=47, from an academic medical center in the USA. | **Ageb****(years, M ±SE)** | 71 ± 9 | A tablet-based educational module regarding PD medications. The module consists of 20 interactive slides accompanied by audio. | Patients' understanding of the topic by knowledge test scores. | Patients' test scores improved with 38% after the module (p<.001).  |
| **Gender****(% female)** | 36 |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | NR |
| **Cognitive functioninge****(MoCA)** | 25.6 ± 3.8 |
|  **Holloway, 2006 [19]**  | To elicit a simplified referral system (care pathway framework), by facilitating the transfer of effective information.*To assess patient evaluation of an information pack regarding health services for PD.*  | * Single group
* Qualitative study as part of a greater mixed-method study.
* Interviews after 1 year of intervention use.
 | N=22, from a single out-patient clinic in the UK.  | **Ageb****(years, M ±SE)** | Range 50-84 | Information pack on local social care, community health and hospital-based services for PD.  | Evaluation of the information package. | Patients were generally positive about the information pack. They used it multiple times during a year. About half of them thought that this pack should be provided to all newly diagnosed PD patients. |
| **Gender****(% female)** | 23 |
| **H&Yc** | 1(n=3), 2-3(n=18), 4-5(n=1). |
| **Disease durationd****(years, M ±SE)** | 10 |
| **Cognitive functioninge** | NR |
| **Kehagia, 2024 [20]** | To develop andImplement a Home Based Care (HBC) pathway, and to evaluate its feasibility, acceptability,and safety.*To evaluate a Home Based Care (HBC) pathway.* | * Single group
* Pre questionnaires
* Post-questionnaires after 6 months of intervention use
* Qualitative evaluation via semi-structured interviews.
 | N=108, who tested the HBC in the UK.n=9 were included in qualitive analyses.  | **Ageb****(years, Median (IQR))** | 71 (12.75) | The Home Based Care (HBC)pathway includes an information package on Parkinson’s disease; Symptom monitoring and management; Parkinson’s service provision and support; and, lifestyle advice. | * Experienced ability to self-manage.
* Qualitative evaluation of patients’ understanding after using HBC.
 | Compared to baseline, more patients felt able to ask for help 6 months after using HBC (68% vs 79%, p=NR). Patients reported an improved understanding of PD which enhanced their ability to self-manage their condition.  |
| **Gender****(% female)** | 31 |
| **H&Yc** | NR |
| **Disease durationd****(years, Median (IQR))** | 5 (5) |
| **Cognitive functioninge** | NR |
| **Leroi, 2010 [21]**  | To estimate the effectiveness and feasibility of sleep therapy for PD patients.*To assess if sleep hygiene education (SHE) affects patient outcomes.* | * RCT in two groups.
1. One group received sleep hygiene education (SHE) (n=7)
2. One group received SHE + sleep therapy (n=8)
* Since both groups received the same educational materials, results were extracted as a single group.
* Pre-questionnaire
* Post questionnaire 2 weeks after intervention.
 | N=15, PD patients with sleep disturbances from a local out-patient neurology clinic in the UK. | **Ageb****(years, M ±SE)** | 72.2 ± 5.0 | * Sleep hygiene education (SHE).
* Basic SHE principles, presented on PowerPoint and handouts.
 | * Patient-reported sleep disturbances (Epworth Sleepiness scale)
* Patient-reported scale from the SHORT-CARE
* Patient-reported Depression (GDS)
* Patient-reported psychiatric functioning (NPI-total)
* Clinically measured motor performance (UPDRS-III)
* Patient-reported QoL (PDQ-39)
* Patient-reported overall well-being (GHQ).
 | All NS.  |
| **Gender****(% female)** | 20 |
| **Mean H&Yc** | 2.4 ± 0.5 |
| **Disease durationd****(months)** | 68.8 ± 12.3 |
| **Cognitive functioninge** | NR |
| **Montgomery, 1994 [22]**  | To assess the effectiveness of the ProPath health promotion program. | * RCT
* Intervention (n=140) vs. control (n=150) group.
* Pre-questionnaires
* Post questionnaires, 6 months after intervention .
 | N=290, setting NR. | **Ageb****(years, M ±SE)** | 68.1 ± 0.9 | ProPath: Tailored written information packages upon study entry and at 2, 4 and 6 months. | * Patient-reported On/Off scores of the UPDRS
* Patient-reported amount of exercise
* Patient-reported medication use
* Patient-reported medical utilization.
 | Compared to the control group, there was a significant increase in patients’ pre to post intervention UPDRS (*M change* = 2.96 vs. 0.37, p<.05), an improved percentage of the amount of exercise (10.6% vs. 20.0%; p<.01), and a decreased daily levodopa dose (61.2mg vs. -0.85mg; p<.05). |
| **Gender****(% female)** | NR |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | 5.8 ± 0.4 |
| **Cognitive functioninge** | NR |
| **Shiraishi, 2023 [23]** | To examine patient, caregiver, and physician satisfaction with an integrated telemedicine digital platform. *To examine patients’ evaluation of online medication instruction* | * Single group
* Post-questionnaire 4 weeks after the last medication instruction.
 | N=30, from one medical center in Japan.  | **Ageb****Years (Mean SD)** | 66.7 (8.5) | Medication instruction by pharmacists, twice face-to-face (weeks 0 and 4) and twice online (weeks 8 and 12)  | Degree of helpfulness in reducing patients’ burden. | Most patients felt that online medication instruction was helpful to reduce their burden (63%). 20% reported it being somewhat helpful, 13% were undecided and 3% felt that it was somewhat unhelpful.  |
| **Gender****(% female)** | 11 (37) |
| **H&Yc** | 1 (n=6), 2 (n=16), 3 (n=4)4 (n=3)5 (n=1) |
| **Disease durationd****years, (Mean ,SD)** | 8.04 (5.4)  |
| **Cognitive functioninge** | NR |
| **Ward, 2004 [24]**  | To test the effects of a home-based educational intervention on patient outcomes. | * RCT
* Intervention (n=52) vs. control (n=53) group.
* Post-intervention questionnaire, 1 year after intervention start.
 | N=84, via 177 general practitioners in the UK. | **Ageb****(years, M ±SE)** | NR | Verbal personalized information, a written tailored version of a standard information package and a leaflet with information regarding PD and self-help organizations – all provided to patients in personal education visits.  | * Patient-reported falls in the following year
* Patient-reported disability and dependency (NEADL).
 | Patients who participated in the education program were more likely to have reported falls in the following year compared to the control group (OR 10.89, p<.05). There was an increase pre to post intervention in their report of disability and dependency with a mean increase of 2.48 (p<.01), which was not compared to the control group. |
| **Gender****(% female)** | NR |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | NR |
| **Cognitive functioninge** | NR |
| **Yi,2021 [25]** | To identify the impact of collaborative pharmaceutical care service (CPCS) on medication safety and patient-reported outcomes. | * Single group
* Pre- questionnaires
* Post-questionnaires, 3 months after intervention.
 | N=92, who participated in the CPCS in China. 20% of the participants received the patient education component. | **Ageb****(years, M ±SE)** | 70.0 ± 9.9 | During patient education by the pharmacist, patients’ questions were answered and they received a leaflet with usage and dosage. | * Patient-reported medication adherence
* Patient-reported QoL (PDQ-39).
 | * Patients who received education, reported an increase in QoL (*M change* = - 0.38, p <.005)
* Other outcomes: NS.
 |
| **Gender****(% female)** | 55 |
| **Median H&Yc** | 2.5, IQR 1.5-3.0 |
| **Disease durationd****(years, M ±SE)** | NR? |
| **Cognitive functioninge** | NR? |

*a, b, c, d, e, f and abbreviations: see caption below Supplementary Table 3.*

Supplementary Table 1c. Interventions: Information in the context of a placebo study - Study characteristics and relevant findings

| **First author, year** | **Study aims and *review specific aimsa*** | **Design** | **Setting** | **Sample characteristics** | **Intervention** | **Patient outcomes** | **Relevant findingsf** |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Carlino,2019 [26]** | To understand the contribution of verbal instructions for levodopa intake on motor performance and fatigue perception.*To assess if patients’ awareness of their levodopa doses is associated with their outcomes.* | * RCT with 3 groups:
1. the *full* group, who received a full dose of levodopa and were told the truth (n=15);
2. the *half* group, who received a half dose of levodopa and were told the truth (n=15); and
3. the *deceit* group, who received a half doses levodopa but were told they received a full dose (n=15).
* Pre and post intervention clinical measurements by blinded neurologists.
 | N=45**,** who had a stable dosage of levodopa for at least 4 weeks. | **NR** | Verbal information provision regarding a single full dose of levodopa, compared with the actual half doses of levodopa administered.  | * Clinically measured motor performance (UPDRS-III)
* Motor performance and fatigue assessment via a clinically measured finger flexor device.
 | * Patients' motor performance measured via the UPDRS-III improved pre to post intervention (thus, after levodopa intake) for all groups. Pre to post improvements in the *full* group *(63%)* and the deceit group *(62%)* did not differ significantly and both showed larger improvements than the *half* group *(44%) (p<.001).*
* Patients' motor performance (i.e., improved finger flexions) increased significantly pre to post intervention for the *full* group *(46%, p<.001))* and the *deceit* group *(29%, p<.05),* but not for the *half* group *(-13%, p<.05).*
 |
| **Mercado,2006 [27]**  | To determine if PD patients' expectations regarding deep brain stimulation (DBS) influences the magnitude of theirimproved motor response. influence their motor response.*To assess if patient awareness of their DBS being ON or OFF is associated with their motor performance.* | * RCT, 4 groups with different conditions: (n=NR)
1. stimulator OFF, patient aware;
2. stimulator OFF, patient unaware;
3. stimulator ON, patient aware;
4. stimulator ON; patient unaware.
* OFF and ON clinical measurements by blind examiners.
 | N=10, wo had previously received bilateral DBS.  | **Ageb****(years, M ±SE)** | 61 (range 42-78 | Patients were aware *vs.* unaware of DBS stimulator being ON or OFF. | * Clinically measured motor performance (UPDRS-III).
 | * There was an increase in patients’ motor performance after turning the DBS ON. This did not depend on patient awareness of the DBS being ON *(p<.001).*
* Aware OFF patients had worse motor performance than unaware OFF patients *(50.7 vs 47.6, p<.05).*
 |
| **Gender****(% female)** | 20 |
| **Hoehn & Yahr (H&Y)c** | NR |
| **Disease durationd****(years, M ±SE)** | NR |
| **Cognitive functioninge** | NR |

*a, b, c, d, e, f and abbreviations: see caption below Supplementary Table 3.*

Supplementary Table 2. Cross-sectional survey studies - Study characteristics and relevant findings

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **First author, year** | **Study aims and *review specific aimsa*** | **Design** | **Setting** | **Sample characteristics** | **Intervention** | **Patient outcomes** | **Relevant findingsf** |
| **Buetow,2008 [28]** | To assess PD patients' experiences and needs regarding PD care.*To assess the relation between the amount of perceived information from a General Practitioner (GP) and seeing a GP specialist as often as wanted.* | Cross-sectional survey study by telephone. | N=422, from New Zealand’s Parkinson's society. | **Ageb****(years, M ±SE)** | 71.6 | Patient-reported amount of received information by either a specialist or GP.  | Patient evaluation of the perceived amount of information and of the frequency of seeing a specialist. | More patients of GPs *(30.6%)* than of specialists *(16.2%)* reported having received insufficient information *(p< .001).* Moreover, receiving enough information from the GP predicted patients’ satisfaction with the frequency of seeing a specialist *(OR: 3.44, p<.001).* |
| **Gender****(% female)** | 43 |
| **Hoehn & Yahr (H&Y)c** | NR |
| **Disease durationd****(years, M ±SE)** | NR |
| **Cognitive functioninge** | NR |
| **Dorsey,2010 [29]** | To assess patient satisfaction and support group use. *To assess patients' evaluation of disease specific information received via either a PD specialist or general neurologist.* | Cross-sectional survey study via internet. | N=726, recruited via the Muhammad Ali Parkinson Disease Registry in the U.S.A. | **Ageb****(years, M ±SE)** | 64.8 ± 10.4 | Patient report of received information. Specifically: 1. information on disease specific topics and
2. information provided by either a PD specialist or general neurologist.
 | Patient-reported satisfaction with received information. | More patients reported to be satisfied with the information received from a PD specialist, in comparison with a general neurologist. This was the case for information about PD *(72.5% vs. 40.9%, p<.0001),* and more specifically for information regarding medication *(61% vs. 48.2%, p<.05),* prognosis *(44.9% vs. 26.4%, p<.001)* and non-drug therapies *(37.5% vs. 19.9%, p<.001).* |
| **Gender****(% female)** | 46 |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | 7.5 ± 6.0 |
| **Cognitive functioninge** | NR |
| **Schrag, 2018 [30, 31]**  | To report patients' experiences of receiving a PD diagnosis and to identify their experienced gaps in care.*To assess the correlation between the amount of received information and patient satisfaction.* | Cross-sectional survey study via internet. | N=1775, from the European Parkinson's disease association. | **Ageb****(years, M ±SE)** | 58.5 ± 10.0 | Patient-reported amount of received information. | * Patients' overall satisfaction with care
* Patient satisfaction with their diagnostic consultation.
 | Patients who reported having received more information, were overall more satisfied with care *(r=0.24, <.001).* More specifically, patients who reported having received more information during diagnostic consultations, were more satisfied with these diagnostic consultations *(r=0.29, p<.0001).* |
| **Gender****(% female)** | 46 |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | 8.2 ± 6.1 |
| **Cognitive functioninge** | NR |

*a, b, c, d, e, f and abbreviations: see caption below Supplementary Table 3.*

| Supplementary Table 3. Qualitative studies - Study characteristics and relevant findings |
| --- |
| **First author, year** | **Study aims and *review specific aimsa*** | **Design** | **Setting** | **Sample characteristics** | **Relevant findings of patients report of the relation between any information and their reported outcomes** |
| Boersma,2016 [32]  | To identify patients' palliative care needs.*To describe patients' experiences regarding neurologists' information provision.* | * Semi-structured interviews
* Data were inductively analyzed.
 | N=30, recruited via medical centers and community support groups in Canada. | **Ageb****(years, M ±SE)** | 68.1 ± 7.1 | Some patients articulated the need for more education. Many patients were dissatisfied with the information they had received. To fill in the gaps, they used online resources, often leaving them dissatisfied. |
| **Gender****(% female)** | 37 |
| **H&Yc** | 1(n=3), 2(n=19), 3(n=3) 4(n=5). |
| **Disease durationd****(months)** | 136.4 ± 77.4 |
| **Cognitive functioninge (MoCA)** | 25.1 ± 4.1 |
| Fothergill,2021 [33] | To understand how people with PD in Kenya go about trying to obtain a diagnosis and what challenges they encounter along the way.*To describe patients' experiences of being informed regarding PD.* | * Ethnographic study with formal in-depth interviews, informal conversations, andobservations.
 | N=55, from private and public clinics in Kenya. | **Median ageb****(years, M ±SE)** | 66.5, range 33 -81  | Some patients reporting not having received a diagnosis at all. Neurologists did not disclose PD, but used vaguer terms. Also, some patients reported receiving too little information. Both experiences led to severe misperceptions. |
| **Gender****(% female)** | 42 |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | NR |
| **Cognitive functioninge**  | NR |
| Haberman,2017 [34] | To explore how PD patients and their spouses discuss their needs, concerns and preferences at the advanced stages of illness.*To describe patients' experiences of being informed regarding PD.* | * In-depth interviews
* Data were thematically analyzed.
 | N=14, recruited via movement disorder practice and support groups in the mid-west of the U.S.A.  | **Ageb****(years, M ±SE)** | 73.3 ± 9.3 | Patients reported having received too little information. This withheld them from making informed plans for the future. |
| **Gender****(% female)** | 50 |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | 12.2 ± 4.2 |
| **Cognitive functioninge**  | NR |
| Nijhuis,2016 [35] | To analyze the facilitators and barriers for evidence-based decision making among PD patients.  | * Focus groups & semi-structured interviews
* Data were thematically analyzed.
 | N=20, recruited by neurologists from 11 Dutch hospitals and via the Dutch Parkinson Association website, purposively selected.  | **Median ageb****(years, M ±SE)** | 63, IQR 49-72 | Patients reported that one barrier to reach a decision was that they did not receive equivalent information about all treatment options, and that they had to search for scattered information themselves.  |
| **Gender****(% female)** | 45 |
| **H&Yc** | NR |
| **Median disease durationd****(years, M ±SE)** | 12, IQR 6-19 |
| **Cognitive functioninge**  | NR |
| Shah, 2022 [36] | To explore how patients self-manage PD.*To describe how patients' perceived information hampers their ability to self-manage their disease.*  | * Semi-structured interviews
* Data were inductively analyzed.
 | N=20, recruited through outpatient clinics in London. | **Ageb****(years, M ±SE)** | 72, range 45-89 | Some PD patients reported having received too little information to properly self-manage their disease. Others felt so overwhelmed by the amount of information, that they suggested some sort of self-management resource with access to information at the time it is relevant. |
| **Gender****(% female)** | 40 |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | <20 |
| **Cognitive functioninge**  | NR |
| Shaw, 2017 [37] | To investigate the current ethical issues in relation to recognizing and managing PD from patients' point of view. *To describe how patients’ ability to cope with their diagnosis is related to the perceived amount of information received.* | * Semi-structured interviews
* Data were inductively analyzed.
 | N=12, from the UK. | **Ageb****(years, M ±SE)** | Range 51-86 | Some patients felt that the more information they would have received, the easier it would have been to cope with PD. Others felt they were given too much information, hampering their ability to cope with the bad news. |
| **Gender****(% female)** | 42 |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | Range 1-24 |
| **Cognitive functioninge**  | NR |
| Tan, 2023 [38] | To explore experiences of treatment burden and capacity among PwP and their caregivers and to identifypotentially modifiable factors. | * Semi-structured interviews
* Data were thematically analyzed.
 | N=9, recruited from PD specialist outpatient clinic in the UK.  | **Ageb****(years, range)** | 59-84 | Patients who were unhappy with their clinicians’ information provision felt unsupported and uncertain about clinicians’ confusing explanations and lack of prognostic information. This made patients learn to self-manage their disease, while seeking other sources of information. |
| **Gender****(% female)** | 44 |
| **H&Y (range)c** | 1-4 |
| **Disease durationd****(years, range)** | 1-17 |
| **Cognitive functioninge**  | NR |
| Troisoeufs,2019 [39] | To describe the roles played by users of internet forums regarding deep brain stimulation (DBS) for PD.*To describe how patients who have experienced DBS might help other patients who are considering DBS surgery.* | * Ethnographic study in which internet forums were searched for information provision regarding DBS.
 | N=NR.Patients who post questions or answers on online forums regarding DBS for PD.  | **NR** | NR | Information from patients who already had undergone DBS, made patients who are considering DBS surgery feel encouraged in their decision to undergo DBS surgery. |
| Zizzo, 2017 [40] | To understand patients’ preferences for participation in medical decision-making.*To describe patients' reaction to disease specific information.* | * Semi-structured interviews
* Data were thematically analyzed.
 | N=20, from a movement disorder clinic in Canada.  | **Ageb****(years, M ±SE)** | 63, range 39-85 | Patients expressed a high information need, especially regarding the progression of their disease. They felt this was necessary to prepare for the future, even if it was upsetting to receive this information. Some patients limited their online search due to this difficulty. Also, some patients felt challenged by coping with the uncertainty of information. |
| **Gender****(% female)** | 50 |
| **H&Yc** | NR |
| **Disease durationd****(years, M ±SE)** | NR |
| **Cognitive functioninge**  | NR |

Caption of Supplementary Tables 1-3:

a*Aim(s) as reported by the authors. In some publications, our review aims were not the primary aims of publications. In those cases, the author (EK) deduced review-specific aims (displayed in italics).*

*bMean age* $\pm $ *Standard error (SE) in years, M ±SE , unless otherwise noted.*

*cH&Y, n per stage, unless otherwise noted. Only reported if publications specified mean (*$\pm $ *SE) or median (IQR). Stage 1: Unilateral involvement only, usually with minimal or no functional disability; Stage 2: Bilateral or midline involvement without functioning of balance; Stage 3: Bilateral disease: mild to moderate disability with impaired postural reflexes; physically independent; Stage 4: Severely disabling disease; still able to walk or stand unassisted; Stage 5: Confinement to bed or wheelchair unless aided.*

*dMean disease duration* $\pm $ *Standard error (SE) in years, M ±SE, unless otherwise noted.*

*eCognitive functioning, mean MMSE* $\pm $ *Standard error (SE), unless otherwise noted.*

*fP-values (if reported) were classified in three categories (p<.05, p<.01 and p<.001).*

ADL, Activities of Daily living; CPCS, collaborative pharmaceutical care service; DBS, deep brain stimulation; GP, general practitioner; H&Y, Hoehn & Yahr classification; IQR, inter quartile range; MCI, mild cognitive impairment; MMSE, Mini-Mental State Examination; MoCA, Montreal Cognitive Assessment; NR, not reported; NS, non significant; PD, Parkinson’s disease; PEPP, Patient Education Program Parkinson; QoL, quality of life; RCT, randomized controlled trial; SHE, sleep hygiene education; UPDRS, Unified Parkinson’s Disease Rating Scale; VAS, Visual Analogue Scale.

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