

Abstracts

Forskningsseminar 2023

Ikke-farmakologisk rehabiliteringsforskning og Parkinsons sygdom

Videns- og kompetencecentret for rehabilitering til mennesker med parkinson

Forskningssessioner:

Patientperspektivet

Fysisk aktivitet og motorisk funktion

Psykosociale og kognitive aspekter i patientforløbet

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Session 2 - Patientperspektivet

2.1. The perspectives of patients with Parkinson's Disease: A qualitative systematic review

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Background

Parkinson's disease (PD) has considerable impact on the quality of life of both patients and their caregivers. Patients' perspectives are a source of vital knowledge that informs health professionals' ability to provide individualised and patient-centered care.

Objective

The aim of this systematic review was to synthesize the perspectives of patients with Parkinson's disease on treatment, care and rehabilitation.

Methods

We conducted a systematic review and searched the following bibliographic databases: MEDLINE, EMBASE, CINAHL, PsycInfo and Scopus for original studies, in June 2020 (renewed December 21, 2021). Grey literature was searched at www.parkinson.org, <http://www.epda.eu.com>, www.apdaparkinson.org and in the OpenSIGLE and HMC databases. We included studies focusing on patients with Parkinson's disease aged 18 or older reporting patients' perspectives on treatment, care and rehabilitation. The results were analysed using thematic synthesis.

Results

Thirteen studies were included, each of them applying qualitative methods and including between 1 and 95 patients. We identified 17 descriptive themes which resulted in three analytic themes: Significance of self, Significance of informal caregivers and peers, and Significance of professionals. Despite the heterogeneity in terms of time elapsed since diagnosis, we found all three themes present in almost all included studies, indicating that patients' perspectives are related to universal human traits rather than to disease-related details. For patients with PD, treatment, care and rehabilitation are intertwined and rarely separable.

Conclusions

Our findings could be important in helping healthcare professionals plan and deliver treatment, care and rehabilitation based on patients' priorities in the context of suffering from a chronic disease. Published January, 2023. DOI: <https://doi.org/10.5430/inep.v13n5p8>

2.2. Hope and Haunting Images The Imaginary in Danish Parkinson's Disease Rehabilitation

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Introduktion

Meget i livet er forestillet: vi håber, vi drømmer, vi frygter, når vi orienterer os mod fremtiden. Vi undersøgte forestillinger om fremtiden i form af håb og "haunting images", når man lever med en progressiv, neurodegenerativ sygdom som Parkinsons sygdom. Sådanne forestillinger kan give indsigt i, hvordan personer med Parkinsons sygdom orienterer sig mod en usikker fremtid, samt en forståelse for de valg, de træffer i rehabilitering.

Metode

Etnografisk feltarbejde med i alt ca. 2 måneders "indlæggelse" på rehabiliteringscenter. 20 personer blev fulgt over tid og sted i 2 år. Metoder: deltagerobservation, interviews og dokumentanalyse. Analysen er fænomenologisk inspireret.

Resultater

Vi fandt, at nogle forestillinger om fremtiden, f.eks. en frygt for at blive "til en grøntsag", mindede om "hauntings" i metaforisk forstand, det vil sige dystre tanker om, hvad fremtiden vil bringe, der som hjemløshed dukker op, forsvinder, dukker op igen og presser sig på i nutiden. Vi viser, at "hauntings" kan være medvirkende til, at den enkelte person gør noget for at undgå eller skubbe realiseringen af "hauntings" ud i fremtiden – ved at insistere på at leve i nuet, passe sin træning og tage del i medicinske forsøg. Vi fandt, at håb var komplekst og mangesidet; det var lokaliseret i træning, medicinsk forskning og andre (f.eks. de der klarede sig godt trods mange år med Parkinsons sygdom, eller fagpersoner), og kunne skabes med andre og arbejdes med. Håb er plastisk: det kan ændres, og deles ud på forskellige håb i et individ. Håb som begreb opfattes ikke nødvendigvis ens.

Konklusion (perspektiver)

Det forestillede er en del af rehabilitering, og det er dermed vigtigt, at forholde sig til det forestillede, som f.eks. personers frygt, håb og drømme. Håb åbnede for dybe tanker. Hvis man som fagperson vil arbejde med håb, bør man være opmærksom på, at håb ikke betyder det samme for alle, samt at arbejdet med håb indebærer tillid, tid og tilstedeværelse, og at det ikke nødvendigvis er alle, som ønsker at dele deres håb med fagpersoner.

2.3. Hvad betyder Parkinsondans for dansere med Parkinson og pårørende? Forskningsresultater belyser vigtigheden af musik og dans for glæde, fællesskab, og eksistentiel håbefuldhed

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Introduktion

Forskningsprojektet "At danse med Parkinson" (et samarbejde med Roskilde Universitet, Tivoli Balletskole og Parkinsonforeningen, 2019-2022) undersøgte følgende spørgsmål: Hvad oplever mennesker med Parkinson og deres pårørende, at Parkinsondans betyder i deres hverdag? Oplægget vil gøre rede for hovedresultater: *musikken som uadskillelig fra dans og glæde, fællesskab på tværs af ligheder og forskelle, og især de eksistentielle vilkår ved kronisk sygdom.*

Metode

Forskningsprojektet havde 3 faser: 1) etnografisk studie på fem Parkinsondansehold, 2) interviews med 43 dansere (mennesker med Parkinson og deres pårørende) og danseinstruktører, 3) fortællerværksteder med samskabelse af analyser (formidlet i populærvidenskabelige tegneseriebøger *Mens vi bevæges*, 2021, oversat til *Moving along* Frølund et al. 2023; se også fx Phillips et al. 2021, 2022a, b, c).

Projektet belyste, hvordan Parkinsondans har potentiale i kraft af forskellige aspekter: emotionelle, fysiske (sanselige), mentale (kognitive), sociale, æstetiske, og eksistentielle. Danserne evaluerede danseaktiviteter som særligt effektive for balance, koordination og humør, med kortvarig (maks. 2 dages) bedring. Motivation blev udtrykt: f.eks. "jeg bliver glad", dansen og musikken skaber et "befriende, ligeværdigt" rum, hvor "tiden forsvinder". Fællesskabet med "humor og uhøjtidelighed" og kvalificerede danseinstruktører, der tager hensyn til Parkinson, var vigtige for fastholdelse. Dansere forbandt dans med komplekse, eksistentielle dimensioner ved at leve med Parkinson - og imødegå fysiske og psykiske forandringer (se fx Christensen-Strynø et al, 2021, under udgivelse a, b).

Resultater

Deltagelse i dans og musik opbygger fællesskaber, bidrager til at revitalisere sensualitet, og forandrer forestillinger om aldring og sygdom. Vi har opnået en nuanceret forståelse af, hvordan Parkinsondans påvirker holdninger til livet med en progressiv, kronisk sygdom på en *håbefuld* måde.

Konklusioner – eksistentiel nyorientering

Projektresultaterne rejser spørgsmål om Parkinsondans som eksistentiel nyorientering. Håb har eksistentielle, spirituelle dimensioner, hvor behandlere ofte træder varsomt, påpeget af ny dansk forskning om tabuer i sundhedsvæsenet. Vi foreslår at håb er en etisk, social handling om at kunne møde modgang uden at fortvivle. Der kan undersøges flere problemstillinger for dans tilpasset Parkinson sygdom i Danmark: 1) vurdering af kvaliteterne ved praksis, bl.a. fordi dans/bevægelse er et fragmenteret fagfelt i Danmark, og 2) klarlægning af eksistentielle aspekter i rehabiliteringstilbud.

2.4. "There is generally no focus on my pain from healthcare staff" Patients experience pain as related to Parkinson's disease and are dissatisfied with pain treatment: a qualitative study exploring the perspective of patients

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Background

Pain is a prevalent non-motor symptom in patients with Parkinson's Disease (PD) and associated with significant quality-of-life-impairments. Yet, no qualitative study has examined how patient with PD experience their pain and pain treatment.

Objective

To understand and report lived experiences with pain in PD.

Methods

Individual interviews (N=15 patients with PD) following a semi-structured interview-guide organized in 7 main topics and 18 subtopics covering both medical and psychological aspects of pain in PD. Data analyzed by a reflexive thematic analysis.

Results

Three major themes emerged: 1) Pain is related to PD: majority of interviewees are confident pain is caused by motor symptoms and/or related to sleep disturbances. 2) Health care professionals neglect pain in PD: frequently, interviewees expressed satisfaction with general PD treatment yet urged health care professions showing interest for their pain. Also, many considered it unclear who is responsible for pain treatment and wished for increased coordination among health care professionals. 3) Treatment of pain is insufficient: self-medication is prevalent. Most interviewees hide or suppress pain. Interviewees broadly reported low and/or temporary effect of alternative pain treatment, yet perceived training as efficient. Multiple interviewees called for research on physical or psychological rather than pharmacological pain treatment.

Conclusions

Patients criticize healthcare professionals for disregarding pain in PD and frequently treat their pain via methods unknown to the professionals such as self-medication. Results suggest treatment of pain in PD must be optimized in various ways including enhancing dialogue with health care professionals and clarifying their responsibilities.

Keywords

Pain, non-motor symptoms, Parkinson's Disease, PD, Qualitative Research, Patient Centeredness, Patient Narratives

2.5. Physical activity and exercise experiences in people with Parkinson's disease treated with Deep Brain Stimulation: A qualitative interview study

Abstractet er en del af en netop submitted forskningsartikel til tidsskriftet *Disability & Rehabilitation*

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Purpose

To explore the experiences of physical activity and exercise, including facilitators and barriers to engagement, in people with Parkinson's disease (PwPD) treated with Deep Brain Stimulation (DBS) (PwaPD) in the years following treatment.

Materials and methods

This qualitative study used semi-structured interviews for data collection among nine PwaPD. Interviews were analysed using the systematic text condensation by the hermeneutic phenomenological methodology of Kirsti Malterud.

Results

The analysis identified three main themes: *It is easier to be physically active, but exercise is a matter of priority* shows why PwaPD might not be more active despite being able to do more; *Time is better spent at home* highlighted that participants experienced a lack of health professional exercise guidance after DBS treatment; *Exercise settings should be accessible, challenging and meet individual needs for socialising* recounts factors that either facilitated and/or acts as a barrier for exercise, such as exercising with others and individualised training. These themes were merged as facilitators and barriers for exercise.

Conclusions

Participants experienced a lack of health professional guidance regarding exercise after DBS. In addition, participants exercised to postpone motor symptoms and often exercised alone and unsupervised, with no adaptation to exercise programs after DBS treatment.

Session 3 – Fysisk aktivitet og motorisk funktion

3.1. Is physical activity, cardiorespiratory fitness, and peak power associated with Parkinson's disease severity?

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Introduction

Increased physical activity (PA) may slow Parkinson's disease (PD) progression. Associations between markers of PA and PD severity could serve as a useful steppingstone to scientific advancement and as justification of further studies evaluating PA.

Objectives

To quantify the associations between PA, cardiorespiratory fitness (VO₂-max), and lower extremity muscle peak power with measures of the Movement Disorder Society- Sponsored Revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS), the Parkinson disease questionnaire-39 (PDQ-39), and the four PD hallmark motor symptoms (rigidity, bradykinesia, stability, and tremor).

Methods

Data were collected from 105 persons with de-novo PD. PA was measured for seven consecutive days using an accelerometer. Peak power and VO₂-max were measured during a chair rise test (linear encoder) and a VO₂-max test, respectively. Analyses included simple and multiple linear regression and hurdle exponential regression.

Results

PA was inversely associated with MDS-UPDRS II + III, rigidity, bradykinesia, and stability scores, as well as with PDQ-39 mobility and activities of daily living (ADL) sub-scores. VO₂-max was inversely associated with MDS-UPDRS III, bradykinesia, and stability scores. Peak power was inversely associated with MDS-UPDRS II + III, bradykinesia, and stability scores.

Conclusion

Weak to moderate inverse associations between physical measures (PA, VO₂- max, peak power) and PD motor symptom severity (MDS-UPDRS II + III) as well as PD core symptoms (rigidity, bradykinesia, stability) highlight the potential benefits of a physically active lifestyle and justify further studies of PA/exercise in PD. Moreover, the inverse association between PA and PDQ-39 mobility and ADL sub-scores calls for further knowledge about the potential effect of PA on quality of life in PD.

3.2 Parkinson's disease and intensive exercise therapy — An updated systematic review and meta-analysis

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In 2015, Uhrbrand et al. published the first review on Parkinson's disease (PD) and exercise entirely based on randomized controlled trials (RCT) applying strict exercise definitions. The present review aimed to update the PD literature by assessing the effects of different intensive exercise modalities: resistance training (RT), endurance training (ET), and other intensive exercise modalities (OITM). An updated systematic literature search identified 33 new RCTs. Qualitative and quantitative analyses were performed. A total of 18 RT, 14 ET, and 1 OITM studies were identified (adding to the 8 RT, 6 ET, and 4 OITM studies identified by Uhrbrand et al. in 2015). RT, ET, and OITM were feasible, safe, and did not worsen PD symptoms. Furthermore, RT, ET, and OITM may positively affect functional outcomes (e.g., balance) and depressive symptoms in PD but inconsistencies across these findings warrant cautious conclusions. Meta-analyses showed that RT had a positive impact on muscle strength (standardized mean difference (SMD)=0.83[95%CI;0.54, 1.12]), functional capacity (Timed Up and Go Test (TUG): SMD = -0.62 [-1.01, -0.24]), and quality of life (SMD = -0.41 [-0.72, -0.09]), while ET had a positive impact on cardiorespiratory fitness (SMD = 0.27 [0.07, 0.47]) and functional capacity (TUG: SMD = -0.21[-0.46,0.04], 6-Min Walk Test: SMD = 0.89 [0.17, 1.62]), and a potentially positive impact on "on-medication" UPDRS-III (SMD = -0.15 [-0.38, 0.09]) and "off-medication" UPDRS- III (SMD = -0.19 [-0.41, 0.04]). In conclusion, RT, ET, and OITM all represent safe, feasible, and beneficial adjunct rehabilitation strategies in PD, with particularly RT and ET showing solid effects.

3.3 Can high-intensity exercise be used to treat fatigue in Parkinson's Disease?

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Abstract

Fatigue has been reported to be the non-motor symptom that, if improved, would make the most marked difference to the daily life of persons with Parkinson's disease (pwPD). Nonetheless, no studies have investigated if exercise holds the potential to decrease fatigue in clinically fatigued pwPD as observed in related populations. A randomized controlled trial with follow up was designed. The primary purposes of the study are to test the hypotheses that pwPD receiving 12 weeks of aerobic exercise will show superior effects on fatigue (i.e., clinically relevant reductions) when compared to a control group (primary hypothesis), and that these effects are sustained after 12 weeks follow up (secondary hypothesis). The results may hold the potential to establish aerobic exercise as a safe, accessible, and low-cost treatment of the most disabling PD non-motor symptom, fatigue. Accumulation of fatigue has profound consequences for pwPD and their relatives, making this study of great importance.

3.4. Rehabilitation i Sano for parkinson patienter

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Denne undersøgelse evaluerer patienter med PD, som kommer til 2 ugers intens rehabilitering i SANO. Patienter kan henvises til bootcamp-rehabilitering i SANO center, Skælskør eller Montebello i Spanien til 2 ugers træning. Hos SANO har Dansk Parkinsonforening gennem 8 år etableret sig stærktrehabilitering for den største gruppe – patient med betydelige behov for medicin mod ADL og QoL men uden demens, fase 2+3. I samarbejde med Parkinson foreningen har SANO i 3 år indsamlet data fra Bootcamp for rehabilitering for personer med Parkinsons sygdom. Hvert år indsendes 8 teams á 10 patienter til 2 ugers genoptræning på SANO, Skælskør. Her behandles ptt med træning, information om fysisk træning, ergoterapi og mange andre aspekter til dagliglivet. En standard sæt data indsamles om alle patienter, der indsendes til SANO. Data vil udleveres af SANO til projektet, med 300 patienter, idet SANO udføres sikre og gentagne tests, med en klinisk velvalideret profil.

Responsive variabler

1. Tempo i fysisk aktivitet, (fysioterapeutevaluering: TUG, 5xSTS, 6 min walk, 10 M walk, MiniBest)
2. ADL (Parkinson rating scale; UPDRS2)
3. Livskvalitet (Parkinson spørgeskema PDQ39)

Data indsamles før rehabiliteringen og efter enten 3 mdr eller 6 mdr. Udviklingen er signifikante variabler der skal evalueres. Patienter, der har været på Boot camp til genoptræning, øger ofte deres aktiviteter og behovet for øget medicin er mindre end for patienten, der ikke kommer for at bestille lejr. Studiet vil blive gennemført inden november 2023.

3.5. Reduktion af tremor ved hjælp af elektrisk stimulation af sensoriske nervebaner

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Tremor er et hyppigt symptom på Parkinsons sygdom, og udgør en væsentlig begrænsning for patienters evne til at udfolde sig i dagligdagen. Elektrisk stimulation af nerver til at skabe ikke-voluntære muskelkontraktioner kan anvendes til at dæmpe tremor. Måleinstrumenter til detektion af tremor og elektrisk stimulation kan indbygges i tekstiler, hvilket gør at denne metode kan implementeres som en diskret og praktisk løsning for patienter. Denne stimulationsteknik har dog to ulemper, der begrænser dens anvendelse i praksis. Stimulationen kan opfattes som ubehageligt, og måden hvorpå musklen stimuleres gør at den udtrættes hurtigt, hvilket gør effekten kortvarig.

Elektrisk stimulation af sensoriske nervebaner fra den kropsdelt, der er ramt af tremor, skaber ikke i sig selv muskelkontraktioner, men nyere studier har vist at denne type stimulation kan have betydelig dæmpende effekt på tremor. Denne teknik har potentialet til at omgå de kendte ulemper ved normal elektrisk stimulation, da sensoriske nervebaner aktiveres ved lave stimulations-intensiteter. De fysiologiske mekanismer bag denne effekt er ukendte, men kan involvere neuromodulation på spinalt og/eller supraspinalt niveau.

Formålet med dette forskningsprojekt er to-delt: 1) Forstå de fysiologiske mekanismer, der gør at stimulation af sensoriske nervebaner kan medvirke til at dæmpe tremor. Denne forståelse vil medvirke til at optimere teknikken i forhold til stimulations-parametre og lokation. 2) Anvende og evaluere effekten en ny teknologi til elektrisk stimulation: Såkaldte high-density elektroder. Modsat tidligere forskning, der har anvendt en enkelt eller få stimulationselektroder, består denne teknologi af op til flere hundrede små elektroder, der ligeledes kan implanteres i fx. tekstiler. Dette giver en langt større fleksibilitet forhold til at stimulere flere nervebaner med høj selektivitet, hvilket vi forventer vil gøre det muligt at optimere graden hvormed tremor dæmpes mens brugerens komfort optimeres. Projektet vil anvende user-centered design for at sikre at systemet ikke alene er effektivt, men også acceptabelt af patienter til brug i dagligdagen.

3.6. Complex rhythmic auditory stimulation for gait in Parkinson's disease

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Introduction

Parkinson's disease (PD) is a neurodegenerative disorder characterized by the loss of dopaminergic neurons in the brain, resulting in motor and cognitive symptoms. Current treatments provide only symptomatic relief, necessitating the investigation of alternative therapies such as rhythmic auditory stimulation (RAS) to address gait deficits. This study aims to investigate the relationship between the pleasurable urge to move to music (PLUMM) during walking, rhythmic complexity, PD, and gait deficits, while exploring potential links to music reward processing. The PLUMM has often been referred to as a groove sensation, where rhythmic patterns elicit embodied responses that are fulfilled by moving the body.

Methods

Participants included individuals with PD and healthy controls (HC) who underwent behavioral questionnaires, groove ratings of different rhythmic complexities, and gait measurements during RAS.

Results

The statistical analysis revealed that PD participants exhibited a significant preference for rhythms of low complexity, whereas HC preferred medium complexity, consistent with previous studies. Interestingly, a significant correlation was found between the difference in groove ratings between low and medium complexities and the sensorimotor subscale of the Barcelona Music Reward questionnaire (BMRQ). This suggests that PD patients who may benefit from RAS already employ music to facilitate movement.

Conclusion

This study contributes to the understanding of PD and gait deficits, demonstrating the preference for low rhythmic complexity in PD patients during groovy RAS. While no significant effects on gait parameters were observed in this small-scale study, previous research supports the potential benefits of RAS. Further research is warranted to comprehensively explore the effects of rhythmic complexity, assess behavioral traits, and validate the therapeutic potential of groovy RAS in Parkinson's disease.

3.7. Psychometric properties for the Danish version of 4 Question Test – a dysphagia screening tool

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Introduction

As Parkinson's Disease (PD) progress, so does the prevalence of dysphagia and objectively dysphagia was measured in in four out of five patients with PD. It is highly recommended to screen for dysphagia in person with PD. The 4-item questionnaire test (4QT) is a new and simple screening measure of dysphagia for the elderly. It consists of four questions: Do you cough and choke when you eat and drink? Does it take longer to eat your meals than it used to? Have you changed the type of food that you eat? Does your voice change after eating/drinking? A positive answer of any of the four items indicates the need for further assessment. 4QT is developed to be fast, simple to apply, and requires no training beforehand. 4QT is translated to Danish according to WHO's guidelines. The aim was to assess the psychometric properties of the Danish version of 4QT in comparison with bed-side tests Volume-Viscosity Swallow Test (V-VST) and Minimal Eating Observation Form – Version II (MEOF-II).

Methods

A total of 73 citizens ≥65 years were included, and 23 were diagnosed with PD. The participants underwent screening with the 4QT as well as tests with the V-VST and MEOF-II. Criterion validity was assessed compared to V-VST, and MEOF-II according to sensitivity, specificity, and predictive validity. Construct- and structural validity was using Confirmatory Factor Analysis and Rasch analysis investigating item- and person fit, Differential Item Functioning (DIF) for sex, age, and primary disease, Local Dependency (LD). Reliability was assessed using Cronbachs coefficient alpha.

Results

For criterion validity, the 4QT showed high sensitivity in participants with PD (94%, and 100% with V-VST and MEOF-II), however, specificity was as expected lower (33%, and 25%). Analyses confirmed the psychometric validity of the 4QT, but also identified potential DIF that should be further evaluated in future studies

Conclusion

The Danish version of the 4QT is a sensitive, but not specific screening tool for citizens with PD and in risk of dysphagia. The final results are presented at the congress. Further studies are required to assess the psychometric properties and to confirm these findings in a larger Danish sample.

Session 4 – Psykosociale og kognitive aspekter i patientforløbet

4.1. Hvilke ikke-farmakologiske interventioner, rettet mod mennesker med PS og kognitive vanskeligheder, er dokumenteret i interventionsstudier.

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Introduktion

Evidensen for interventioner ved Parkinsons Sygdom og kognitive vanskeligheder er sparsom og de fleste interventionsstudier er desuden af svag metodologisk kvalitet. Interventioner målrettet kognitive vanskeligheder varierer også betragteligt, både hvad angår struktur, proces og outcome. Der er brug for et overblik over ikke-farmakologiske interventioner til målgruppen. Formålet med dette projekt er derfor at gennemføre et scoping review og systematisk at kortlægge interventioner til mennesker med Parkinsons sygdom og kognitive vanskeligheder. Det vi søger at få svar på er, *hvilke ikke-farmakologiske interventioner, rettet mod mennesker med PS og kognitive vanskeligheder, er dokumenteret i interventionsstudier.* Reviewet er tænkt som en første etape i et større projekt, med fokus på livet med Parkinsons sygdom i tyndt befolkede områder. Næste etape er en analyse af allerede indhentede kvantitative data, som bl.a. handler om livskvalitet og funktionsevnebeskrivelse på Færøerne og Als, hvorefter en komparativ analyse vil blive udført mellem de to geografiske områder. Tredje etape omfatter kvalitative interviews, hvor opmærksomheden rettes både mod håndtering af hverdagslivet og mod betingelser for hverdagslivet, herunder adgang til og brug af offentlige ydelser, kulturelle og civilsamfundsressourcer. 2

Metode

Reviewet gennemføres som scoping review, som er særligt velegnet til at undersøge og identificere omfanget og området af forskning inden for et bestemt emne. Det hjælper med at afklare, hvilke forskningsspørgsmål der er blevet undersøgt, og hvilke områder der er blevet dækket, samt at identificere eventuelle huller i litteraturen. Review-protokollen publiceres i Open Science Framework og afrapporteres efter PRISMA tjekliste for Scoping Reviews. Der søges i PubMed.gov (National Library of Medicine), Embase.com (Elsevier), CINAHL (fra EBSCO), Cochrane Library og Open Science Framework. Inklusionskriterier omfatter Parkinsons sygdom som aktionsdiagnose, Kognitive vanskeligheder, og interventioner som er målrettet problemer, som er eksplicit relateret til kognition. Interventioner i form af medikamentelle terapier, vitaminer og kosttilskud ekskluderes, hvor disse står alene. Inkluderede papers omfatter interventionsstudier og reviews som er peer-reviewet og publiceret i internationalt anerkendte tidsskrifter. 'Grey literature' inkluderes efter specificerede kriterier.

Resultater

Preliminære resultater vil blive præsenteret på seminaret

Konklusion

Forklaring om hvordan dette projekt vil danne grundlag for videre arbejde vil blive præsenteret på seminaret.

4.2. Kognitive vanskeligheder ved Parkinsons sygdom: sociodemografiske karakteristika, funktionsevne, livskvalitet og ikke-mødte rehabiliteringsbehov hos danskere med og uden selvrapporterede kognitive vanskeligheder

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Knud Juel, professor emeritus, Statens Institut for Folkesundhed, SDU

Kristian Winge, overlæge, lektor, Neurologisk afdeling, Slagelse Sygehus, og Syddansk Universitet

Tina Broby Mikkelsen, datamanager og forsker, REHPA, Videncenter for Rehabilitering og Palliation, Odense Universitetshospital, Nyborg, Danmark; Klinisk Institut, Syddansk Universitet, Odense, Danmark

Introduktion

Parkinsons sygdom (PS) ledsages af motoriske såvel som non-motoriske symptomer. Kognitive vanskeligheder er kendte non-motoriske symptomer. Omkring 20% af personer med 'de novo' PS oplever lette kognitive vanskeligheder (MCI), som kan være forløber for demens. Efter 20 års sygdom ses demens hos over 80% af personer med PS, med store individuelle variationer. Der er i Danmark og internationalt stigende opmærksomhed på rehabilitering af mennesker med PS og kognitive vanskeligheder. For at udvikle og målrette rehabilitering mangles viden om målgruppen, deres karakteristika, funktionsevne og livskvalitet og deres ikke-mødte behov for non-farmakologiske indsatser.

Metode

Data er baseret på en national spørgeskemaundersøgelse fra 2020. Respondenter er inddelt i to grupper med hhv. uden selvrapporterede kognitive vanskeligheder, identificeret på udvalgte items i PDQ39. Der er gennemført sammenlignende analyser ift. sociodemografiske karakteristika, sygdomsgrad, tid siden diagnose, livskvalitet og ikke-dækkede behov for non-farmakologiske indsatser (patientuddannelse, livsstilsinterventioner, psykosocial støtte, funktionsevne og omgivelsesmæssige tilpasninger). Svar fra selv-respondenter og proxy-respondenter er analyseret hver for sig.

Resultater

I alt indgik 7039 danskere med PS i undersøgelsen. Af disse rapporterede 31% af deltagerne at opleve kognitive vanskeligheder. Ikke-publicerede resultater præsenteres på dagen.

Konklusion

Præsenteres på dagen.

4.3. Empowerment of People with Parkinson's disease: development, testing and evaluation of a cross-sectoral, intervention-based self-management program

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Background

Living with Parkinson's disease (PD) involves living with a variety of symptoms, each of which affects many aspects of everyday life and quality of life (QoL). To support People with PD (PwP) and their caregivers to develop skills and provide them with tools to adapt to life with PD, increase QoL, as well as promote self-management, there is a need for education in all aspects of the disease, including psychosocial aspects.

Objectives

The overall purpose of this study is to develop, test and evaluate the results of a self-management program targeted PwP with the aim of empowering both PwP and caregivers.

Methods

85 PD-patients (Hoehn&Yahr score 1-3), and their caregivers will be included in the study. Participants are recruited consecutively from Movement disorder Clinics at two hospitals, neurologists in municipalities and a Rehabilitation Center. The study is divided into three phases:

Study 1: Exploratory, qualitative study. Data on how PD-patients describe the needs in everyday life, self-efficacy, coping strategies, and ability to manage symptoms/challenges, and clinical perspectives, was obtained through workshops and focus-group interviews with PwP, caregivers, healthcare professionals and other stakeholders (13 participants in total)

Study 2: Intervention study. Based on the results in Study 1, an 8-week self-management program were developed. This consists of 6 educational sessions, monitoring of motor and non-motor symptoms by the Parkinson KinetiGraph™ (PKG At Home), individual goal-setting, home visits by PD-nurse and mindfulness-sessions. Primary outcomes are changes in scores of Health Education Impact Questionnaire (HeiQ) and Health Literacy Scale (HLS-14). Secondary outcome measures are changes in QoL-score (PDQ-39), The General Self-efficacy Scale (GSES), Unified Parkinson's disease Rating Scale Part-II (UPDRS-II), algorithm outcomes regarding motor symptoms and fluctuation score measured by the PKG, and numbers of contacts to the clinics (evaluated 6 Months before and after the intervention).

Study 3: Follow-up study 3 and 6 Months after the intervention. *Trine Hørmann Thomsen, MScN, PhD, Movement disorder Clinic, Rigshospitalet, Denmark.*

Results

Study 1 was completed in September 2022. In June 2023 the first three groups (42 PwP and 29 caregivers) will have completed the self-management program (Study 2). The intervention phase is expected to finish in the first quarter of 2024.

Conclusion

In Study 1 a self-management program tailored PwP and their caregivers was developed with Patient&Public involvement and is now being tested. The results of Study 2 and 3 will be analyzed when all 85 PwP have completed the self-management program.

The study will also be presented at the World Parkinson Congress July 2023

4.4. Effects of STN-DBS on response inhibition and verbal fluency in patients with Parkinson's disease

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Introduction

Deep brain stimulation (DBS) of subthalamic nucleus (STN) is a well-established treatment alternative for motor symptoms in patients with advanced Parkinson's disease (PD) when dopaminergic medication is no longer a viable option due to off-periods and dyskinesia. There are, however, reports of mild adverse effects on impulsivity and verbal fluency from the treatment. The underlying mechanism is still not well understood, but the basal ganglia have been associated with both response inhibition and executive functioning. And thus, differences in electrode placement within STN have been suggested as a potential cause.

Methods

To address this, we used magnetoencephalography (MEG) to investigate eight PD patients with STN-DBS performing the Stop-Signal Task and verbal fluency tasks under three different treatment settings (always off medication): (1) DBS turned off, (2) DBS turned on at more ventral contacts bilaterally within STN, and (3) DBS turned on at more dorsal contacts bilaterally within STN.

Results

Our preliminary analyses show no noticeable differences in the stop-signal reaction time (SSRT) between the two DBS settings, nor for when DBS was turned off. However, the MEG results may reveal subtle differences in the brain processes involved in response inhibition and verbal fluency.

Discussion

The preliminary results are not in direct alignment with previously reported impaired response inhibition and verbal fluency following treatment with STN-DBS. However, we note the relatively small sample size, and pending MEG results may reveal the potential for adapting the DBS stimulation to compensate for adverse cognitive effects of the treatment.

Keywords

response inhibition, verbal fluency, Parkinson's disease, deep brain stimulation, magnetoencephalography

4.5. Brug af partnerbåret mikrofon for at optimere kommunikation mellem ægtepar - En tværfaglig audiologopædisk intervention belyst via en caseundersøgelse

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Introduktion

Op i mod 90% af mennesker med parkinson vil på et tidspunkt udvikle dysartri¹. Dysartrien kendetegnes ved svag stemmestyrke, utydelig artikulation, monoton tale og tendens til hurtig tale og stammen². Det kan have store konsekvenser for ens livsførelse og -kvalitet at blive ramt på sin kommunikation. Der findes forskellige logopædiske interventionstyper for at forbedre kommunikationen herunder et evidensbaseret program for at øge stemmestyrken: Lee Silverman Voice Treatment (LSVT LOUD)³ og programmer til samtalestøtte med involvering af pårørende f.eks. "Better Conversations With Parkinson's"⁴. Herudover kan kommunikationshjælpemidler afprøves f.eks. en stemmeforstærker for at optimere kommunikationen. Pga. gennemsnitsalderen ved parkinson hænder det ofte, at ægtefælle har en hørenerdsættelse, hvilket besværliggør kommunikationen mellem parret yderligere. En partnerbåret mikrofon koblet til ægtefælles høreapparat kan derfor udgøre en effektiv løsning for at forbedre kommunikationen.

Metode

Den audiologopædiske intervention beskrives på baggrund af en caseundersøgelse. Der er tale om et par, hvor kvinden er 76 år og har været diagnosticeret med idiopatisk Parkinsons sygdom i 3 år. Hun har moderat dysartri og har haft begrænset effekt af den logopædiske intervention, da hun er kognitivt ramt og dermed ikke på eget initiativ kan øge sin stemmestyrke. Ægtefælle på 77 år har et moderat bilateralt perceptivt høretab. Han anvender høreapparater, Oticon Ruby 2. Der iværksættes en afprøvning af Oticon ConnectClip. Oticon Connectclip er en lille partnermikrofon, der sender lyd direkte op i høreapparaterne hos personen med høretab. I nærværende eksempel foregår det ved, at kvinden med Parkinson bærer mikrofonen om halsen, hvorved hendes tale sendes trådløst til ægtefælles høreapparater.

Resultater

Kommunikationen parret imellem er optimeret markant. Parret kan igen kommunikere, når de kører i bil, de har færre misforståelser, udtrættes i mindre grad og ægtefælle oplever en trykthed ved at kunne høre, hvis ægtefælle pga. sin parkinson skulle falde, mens hun er i et andet rum.

Konklusion

Brug af partnerbåret mikrofon hos ægtepar, hvor den ene part har parkinson og den anden part har en hørenerdsættelse, kan være en relevant og effektiv løsning for den indbyrdes kommunikation.

4.6. Key points to consider in future pathways in Parkinson's disease.

Lessons learned from the international OPTIM PARK study

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Objective

Disease management in Parkinson's disease is complex and a difficult task for people with Parkinson's disease and their family carers to manage on their own. It is a challenge to be knowledgeable of the cross-sectoral and community-based resources available to support better living with Parkinson's disease as availability of resources will vary from community to community, which may additionally hamper the possibility for timely support. Health care professionals who are not specialized in Parkinson's disease, may also be unaware of resources available and cross sectoral collaboration seem absent. Although integrated care models are emerging, a coordinated and structured cross-sectoral pathway thus seemed to be missing in the involved countries. The OPTIM-PARK intervention was developed and tested in Denmark, Norway, Spain and UK. The intervention focused on optimisation of community resources and systems of support through a communitybased coordinator.

Methods

The intervention is evaluated through a mixed methods approach, involving data from questionnaires, coordinator logs and qualitative interviews with participating agents, people with Parkinson's disease and Family carers.

Results

The presentation will highlight how the intervention enhances accessibility, individualised support and use of appropriate resources. The aim is to identify insights that will support the development of integrated and cross-sectoral care in Parkinson's disease management.

Conclusion

We will present benefits from establishing a coordinated pathway for People with Parkinson's disease and their Family Carers, and highlight important key-points to consider when developing cross-Sectoral pathways in Parkinson's disease.