**Supplementary table 3:** **Data extraction for 16 included studies.**

Non-randomised studies (JBI data extraction)

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| **Study Author, Date, Country.** | **Study type.** | **Setting (context) [Profession].** | **Neurological Condition** | **Participant Characteristics** | **Patient Reported Experience Measure.** | **Prevalence results. Mean PREM scores (SD)** |
| Rosti-Otajärvi et al 2014, Finland. | Observational cohort (prospective). [Single centre] | Hospital Outpatient (neuropsychological intervention) [Neuropsychologists] | **MS: N=56.** Type: Relapsing remitting. Mean years since diagnosis 9.3 (SD 6.7). | N=56 (M=13; F=43); Mean age: 43.7 (SD 8.8); Ethnicity not reported. | **Working Alliance inventory (WAI)- short form (client).** | Mean total score (for client) 77.2/100 (SD 4.6) (before the end of last session); WAI task factor -utility and efficacy of things done in rehabilitation (Mean 25.5 (SD 1.9); WAI bond factor- personal bond between patient and therapist (Mean 25.2 (SD 2.0); WAI Goal Factor - patient therapist agreement on goals (mean WAI goal 26.4 (SD 1.6) |
| Buecken et al 2012, Germany | Descriptive Survey [Single centre] | Care Facility (End of Life) [Physician] | **MS: N=541.** Type: Relapsing remitting n=132; Primary Progressive n=117; secondary progressive n=228 Mean time since diagnosis: 15 (SD9.1) | N=541 (M=190; F=383) Mean Age: 51.6 (SD10.8) [32 did not answer CARE] Ethnicity not reported. | **Consultation and Relational empathy Questionnaire (CARE). sent to respondents after consultation.** | Mean score of 39.3 /50 (SD 9.1). Individual scores ranged from 10/50 (no empathy perceived) (0.6%) to 50 (maximal empathy perceived) (12.4%). |
| Marrie et al 2013, US | Descriptive Survey [multicentre] | NARCOM's registry (Information provision) [multiple sources -professional, non-professional, online] | **MS: N=8573.** Mean age of diagnosis: 38.5 (SD 9.7) | N=8573 (M=1924 F=6649) Mean age: 56.6 (SD 10.5) Ethnicity: White 7610/7972 (95.56%); Non white 3.62/7972 (4.54%) | **Health Information National Trends Survey (section 2 - info seeking about MS). Completed 2011 - on paper or online.** | 28.20% 2131/7556 felt that it took a lot of effort to get the information they required, while 28.15 (2120/7531) felt frustrated during their search. 39.86% (2998/7521) were concerned about the quality of the information they gathered. Most trusted information source was physician, with 97.94% (8318/8493) reporting they trusted a physician some or a lot. |
| Minden et al 2013, US | Descriptive Survey [multicentre] | MS centre (Mental Health support) [neurologist, primary care physician, nurse) or mental health professional (psychiatrist, psychologist, social worker, psychiatric nurse, mental health or substance abuse counsellor) or self-help/support groups, clergy, online groups, chats, message boards] | MS: N=3384; Type of MS: Relapsing Remitting n=1597; Secondary Progressive n=981; Primary Progressive n= 453; Other n=142 Years since diagnosis: ≤ 5 years n= 1205; 6-10 years n= 843; 11-15 years n=532; 16-20 years n=351; > 20 years n=324. | N=3384 (M=788 F=2596) Age 18-34 n=428; 35-44 n= 9111; 45-54 n =1133; 55-64 n=689; 65+ n=196). Ethnicity: White 3064/3384 (90.5%); African American 5.9/3384 (4.8%); Hispanic 54/3384 (1.6%); Other race 67/3384 (2%). | **Experience of Care and Health Outcome Survey (ECHO survey).** | Mean score 7.5/10 (SD2.3) for quality of mental health treatment for those who received it. Positive experiences of feeling safe (97.0%) maintained confidentiality (96.4%), showed respect (93.9%), listened carefully (93.5%), explained things well (92.7%), knowledgeable about MS in general (90.3%), gave them enough time (89.3%), up to date with their MS and MS care (89.2%), Felt as involved as they wanted to be in their treatment (81.4%). Fewer positive experiences for providers being prompt (79.5%), informed about medication side effects (74.7%), responsive to cultural needs (74.0%), time taken before seen (66.4%), receiving information about self help and support groups (57.3), receiving information about other treatment options (44.1%). Only 25.4 % reported usually or always getting the mental health care they needed. |
| Normann et al 2012, Norway | Descriptive survey [Single Centre] | Physiotherapy assessment, treatment, information and instruction in self assisted exercises [Physiotherapist] | MS: N= 64 Type or years since diagnosis not reported. Ambulatory Independence: Independent n = 8; Uses walking aids n=7 and uses wheelchair n=8 | N=64 (M=18 F=54). Mean age: 45 (range 26-80). Ethnicity not reported. | **Outpatient Experience Questionnaire (OPEQ):** 1 - 2 weeks after consultation | Patients experiences of interpersonal elements, professional skills, information provision and guidance were positive (9.1/10 (SD0.5) Information about potential development of the condition less positive (6.4/10 (SD1.5) |
| Swaine et al 2017, Canada | Descriptive Cross sectional validity study [multicentre] | TBI rehabilitation (acute, inpatient and outpatient provision (data extracted for outpatients. [MDT - professions not specified] | ABI: N=330 for outpatient phase. Years since injury for outpatients not reported. | N=330 for outpatient phase. Characteristics of outpatients not reported. Ethnicity not reported. | **The Perception of Quality of Rehabilitation Services (PQRS-Montreal)** administered by trained interviewer | Mean scores for outpatients' phase: Ecological approach 3.61/5; Client centred approach; 3.89/5, Overall team quality 4.31; Service Continuity 4.16); Service Availability 2.85. SD not reported |
| Stepleman et al 2016, US | Descriptive survey [Single Centre] | MS Centre (sexual satisfaction) [Physician] | MS: N=73 no details reported | N=73 (M=9 F=64) Mean age 43.53+10.4 Ethnicity: Caucasian N=44 (60.3 %) African American N=27 (37%); Latino/Hispanic 1 (1.40%); Other 1 (1.40%) | **Patient Satisfaction Questionnaire (PSQ-18) -** administered at appointment | Total average score: mean 3.92+0.65; range 1.61-5 [Co-efficient Alpha 0.9]; General satisfaction 4.03+0.90; range 1-5 [Co-efficient Alpha 0.76]; Technical quality 4.11+0.77; range 1.25-5 [Co-efficient Alpha 0.8]; Interpersonal 4.40+0.67; range 1.5-5 [Co-efficient Alpha 0.64]; Communication 4.05+0.83; range 1-5 [Co-efficient Alpha 0.58]; Financial aspects 3.36+1.12; range 1-5 [Co-efficient Alpha 0.6]; Time 3.96+0.94; range 1-5 [Co-efficient Alpha 0.79]; Access/convenience 3.53+0.87; range 1-5 [Co-efficient Alpha 0.71] |
| Van de Eijke 2012, Netherlands. | Descriptive: Validation of patient experience measure [multicentre] | Parkinson's Disease Care Provision from PD Clinics | PD: N=875 Self-reported Hoehn and Yahr stage between 1 and 3. | N= 875 (M=60.9% F=39.1%) Mean Age 69 (SD 10); Ethnicity not reported | **Patient Centred Questionnaire for Parkinson's Disease (PCQ PD). Posted to participants.** | The overall patient-centeredness score (OPS)was moderate 1.69/3 (SD 0.45). ‘Emotional support’ 1.05/3 (SD 0.90) and ‘provision of tailored information’ 1.18/3, (SD 0.57) subscales received lowest experience ratings. Involvement in decision making received next lowest negative experience rating 1.78 (0.61. Continuity and collaboration of professionals 2.24 (SD 0.68); Empathy and PD expertise 2.55 (0.48); Accessibility of health care Mean 2.63 (SD0.53) received positive ratings. |
| Van de Eijke,2015, US and Canada | Descriptive Survey [multicentre] | Parkinson's Disease Centres (n=40) (Specialist consultation) [neurologist] | PD: N=955 Type: PD n= 928; Parkinsonism (MSA and PSP) n= 27. Self-reported Hoehn and Yahr stage HY1 n= 306; HY2 n=190, HY3 n=374, HY4 n= 49, HY5 n=22 | N= 955 (M=578 F=377). Median Age 69 (range 32-93). Ethnicity: Caucasian n=671 (93.6%) African American n=17 (2.4%); Asian n=14 (2%); American Indian or Alaskan native n=2, (0.3%); Other n= 13 (1.8%). | **Patient Centred Questionnaire for Parkinson's Disease (PCQ PD).** | Overall Patient centredness Score ranged from 1.87/3 (1.74–2.00) for worst performing centre to 2.23/3 (2.11–2.36) for the best performing centre. Information subscale [mean 1.62/3 (SD 0.62)] and collaboration subscale [mean 2.03/3 (SD 0.58)] received the lowest experience ratings. Accessibility of care [mean 2.49 (SD 0.55)] and empathy [mean 2.63 (SD 0.52)] received the highest experience ratings. |
| Kessler et al 2019, Canada | Observational Mixed methods [single centre] | PD clinic. (Collaborative care) [tertiary Nurse, Speech Pathologist, Physiotherapists, Neurologist, Family physician, Support group facililitator] | PD: total N=57; Mean years since diagnosis 7.2 (SD4.6). Hoehn and Yahr not specified. | N=57. (M=37 F=20) Mean age: 66.3 (SD8.3); Ethnicity not reported. Caregivers n= 31 (M=6 and F=24; Mean age 66.0 SD(10.5) | **The Patient Assessment of Chronic Illness Care plus (PACIC+) survey)** administered over a 3- month period when patients attended clinic. | Mean (SD) for each dimension of the PACIC: Activation = 3.5/5 (1.17); Decision support 3.1/5 (o.99); Goal setting =2.5/5 (0.97; Problem solving/contextual counselling =3.1/5 (1.16); follow up/coordination =2.1/5 (1.01) and 5A's =2.9/5 (1.06). Over 50% patients ranked goal setting and follow up/coordination as 'generally not occurring' or 'never occurring'. |
| Schonberger et al 2006, Demnark. | Observational Cohort (prospective) [Single centre] | Rehabilitation Centre (Holistic neuropsychological rehab: cognitive, physical and social training for 14 weeks, 4 days/week. [Neuropsychologist, physiotherapist, speech therapists, occupational therapist, special education teacher. Therapist case manager allocated/client] | ABI: N=86. Type: TBI (n=27), CVA (n=49), Other (n=10). Mean years since injury 1.22 (SD 1.08). | N=86 (M=55 F=31) Mean age 44.9 (SD11.5) Ethnicity not reported. | **Working Alliance Inventory (WAI) -short form - client.** used at 2, 6, 10 and 14 weeks. Assistance from research/administrative staff or trainees when needed. Rated 1 - 7 (1 = not at all) and (7='a lot') | Mean total score (for client) across four timings was 5.65 (SD0.70); at 2 weeks 5.59 (SD0.78), at 6 weeks 5.71 (SD0.76) at 10 weeks 5.62 (SD0.83) nd at 14 weeks 5.73 (SD0.83); Mean task score across the four timings was 5.73 (SD0.75). At 2 weeks 5.65 (SD0.91); at 6 weeks 5.68 (SD0.91), at 10 weeks 5.70 (SD0.92) and at 14 weeks 5.86 (SD0.81). Mean Bond score across four timings was 5.84 (0.88); at 2 weeks 5.95 (SD0.93); at 6 weeks 5.89 (SD 0.93) and 10 weeks 5.75 (SD0.98) and at 14 weeks 5.90 SD0.98). Mean goal score across the four timings was 5.38 (SD0.95); at 2 weeks 5.19 (SD0.10); 6 weeks 5.58 (SD1.00) at 10 weeks 5.46 (SD1.02) and 14 weeks 5.46 (SD1.14). |
| Poncett et al 2017, France | Observational Mixed Methods (prospective) [single centre] | Rehabilitation department (multidisciplinary rehabilitation: training in activities of everyday life 5 days/week for 7 weeks) [Physiotherapist, Occupational Therapist, Clinical Psychologist, Speech and Language Therapist, Psychiatrist, neuropsychologist, social worker] | ABI: Brain Injury total N=33. Type of injury: TBI 15.1%, Stroke 63%, other 21.9% Mean years since injury not reported. | N= 33 (M=17 F= 16) Mean age 43.6 (SD15.6). Ethnicity not reported. | **Perception of Quality of Rehabilitation Services (PQRS Montreal) Questionnaire:** Administered by independent evaluator (30- to 45-min interview) week after end of program. | Highest Mean (SD) scores equal or more than 3.5/5) for following dimensions: ecological approach (3.63 (SD1.41), client-centred approach (3.85 (SD1.25), overall team quality (4.31 SC (0.94) and service continuity (4.04 (1.01). Lowest mean (SD) scores equal or less to 2.5/5 for service accessibility (2.51 (SD 1.20) support re impact of injury on sexuality 2.03 (SD 0.81) and processes involving family and friends (1.61 (0.81), or communication with employer or 2.00 (0.89) or work colleagues (2.86 (1.46). |
| Prescott et al 2019, Australia | Observational Cohort (prospective) [multicentre] | Outpatients and private community services. (Rehabilitation goal setting within individual disciplines) [occupational therapists, speech pathologists, physiotherapists, neuropsychologist, social worker]. | ABI: Brain Injury total N=44. Type: TBI (n=25), Stroke (n=6), SAH or SDH (n=5), Hypoxia or tumour (n=5) Other (n=3). Mean years since injury 395 days (SD 746.3) | N=44 (M=28 F=16) Mean age 37.5 (SD 12.6); Years of Education 13 (SD2.4); Ethnicity: Oceanian n=37; North West European n=2; Southern and East European (n=2; Sub Saharan African n=2). | **Client-centredness of Goal Setting Scale (C-COGS) (after the goals were set).** | Mean total scores on C-COCS of 44.95/50 (SD4.64). Goals subscale: Mean perceived ownership/importance or relevance of goals 17.98/20 (SD2.02). Participation sub scale: mean perceived participation in setting goals 26.97/30 (SD2.81). |
| **Key:** Parkinson's Disease = PD; Multiple Sclerosis = MS; Acquired Brain Injury = ABI (TBI= Traumatic Brain Injury; SAH = Sub Arachnoid Haemorrhage). SD= Standard Deviation | | | | | | |

S1 Randomised Controlled Trials (JBI data extraction)

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| **Author, date, country, [design]** | **Interventions (n randomised)** | **Condition.** | **Participant Characteristics** | **Patient Experience Measure** | **Follow Up** | **Follow up Rates Intervention -control)** | **Prevalence (Mean score and SD)** | **Results** |
| Connor et al 2019, US. [Single centre, two group RCT]. | Intervention. Nurse led Guided Care management for veterans with PD n= 162. Usual Care for PD n=166 **Multi modal [Multidisciplinary]** | Parkinson's Disease. At least two ICD - 9 codes for diagnosis of PD over the last 12 months. | **N= 328 Veterans with PD. Guided care Management Intervention n= 162** (M =164 F=2)Mean age 69.6 (SD 10.1) Ethnicity: African American n= 9 (5.6%); Asian American n=3 (1,9%); First Nation/Alaskan Native 2 (1.2%); Caucasian or Euro American n= 125 (77.2%); Hispanic or Latino n=21 (13.0%); Native Hawaiian or other Pacific Islander n=0; Other n=0  **Usual Care n = 166** (M=155 F= 11)Mean age 71.3 (9.2) Ethnicity: African American n=11 (6.6%); Asian American n=0; First Nation/Alaskan Native n=3 (1.8%); Caucasian or Euro American n=131( 78.9); Hispanic or Latino n=16 (9.6) Native Hawaiian or other Pacific Islander n=3 (1.8%) Other n= (0.6%) No significant difference in demographics between groups. **Overall mean age 71.** | **Patient assessment of chronic illness care (PACIC).** | 6, 12, 18 months | At 18 months 71% (intervention) 67% (Usual Care) | **Intervention PACIC score at 18 months 2.34/5 (0.84). Usual Care PACIC score at 18 months 2.41/5 (0.83).** | No significant difference between groups. |
| Eyssen et al 2013, Netherlands. [Cluster randomised control trial. Multiple sites]. | **Client centred occupational therapy** based on Canadian Client centred Process framework delivered across 7 centres (n= 156). OT's undertook 2 day training in client centred practice followed by five booster sessions commencing 4 weeks after the initial course during data collection period **Usual care occupational therapy** delivered across 7 centres (n= 113).No training received by OT's. **Multimodal (Single discipline)** | **Multiple Sclerosis: any type of MS.** | **Adults with MS N=255.**  **Client Centred Occupational Therapy Intervention:** (M=45 F= 110) Mean age 44.4 (SD 11.4); Mean years since diagnosis 8 (7.8)  **Usual Care Occupational Therapy Group:** (M= 39; F=74) Mean age 47.1 (SD9.9).; Mean years since diagnosis 8.3 (SD 9.2) At Baseline significant difference found between intervention and control group for age (44 v 47 years p=0.05), type of MS: 39% v 21% relapsing remitting, 16 % v 14 %) primary progressive, 12%v26% secondary progressive, 6% v 4 % progressive relapsing. Ethnicity not reported. | **Quote EEE (Quality of Care through users' eyes)**: | 4 months, 8 months | At 8 months 94.9% Client centred OT; 94.7% Usual Care OT | Intervention Quote EE scores: At 0-4 months Quality of therapy (information importance scale) 0.52 (p=0.02) and total information importance scale 0.33 (p=0.05). At 0-8 months quality of therapy (information importance scale) 0.64 (p=0.00) and total 0.43 (p=0.02). At 4-8 months Quality of therapy (information performance scale) 0.07 (p=0.04). Quality therapy costs 0.61 (p=0.05) | No significant difference on client centredness of the organisation or therapeutic process and relations. **Significant difference in favour of Client centred OT for Information importance scale at 0-4 months (p=0.02) and at 0-8 months (p=0.00) AND information performance scale at 4 - 8 months (p= 0.02). Significant difference in favour of Usual Care for costs quality index.** |
| Ehde et al 2015, US. (Single centre, blind, 2 parallel groups). | Group A: 8 week individual telephone administered self - administered (T-SM) Group B: 8 week telephone administered MS education intervention (T- Ed) Delivered by social workers (M level) and psychologist (Doctoral) Training and supervision from psychologist during intervention | Multiple Sclerosis: any type of MS with fatigue, chronic pain or depressive symptoms. | Adults with MS. Age range 25 - 76  Group A (T-SM). n=75 (M=8 F=67)  Group B: (T-Ed)) n= 88 (M=13 F=75) Baseline participant characteristics were balanced (see table 2) except more T-ED participants were working <20h/week and reported higher average PHQ-9 scores. | Working Alliance Inventory Short Form - Clients) | post treatment (9 weeks post randomisation) and 6 -12 months post randomisation. . | At 12 months 80% T-SM; 91% T-Ed. | Both groups reported significant improvement in therapeutic alliance from baseline to post treatment (p < 0.05). T-SM participants reported a stronger working alliance score than T-Ed (Group A: Intervention Median 82 v Group B Medium 72 (p < 0.001) and stronger agreement on therapeutic bond, tasks and goals (p<0.001). | Both telephone interventions resulted in improvement of therapeutic alliance from baseline to post treatment (p <0.05). **WAI score significantly higher for T-SM participants (p<0001) and there were stronger agreement on therapeutic bond, tasks and goals (p<0.001)** |
| **Key**: PD=Parkinson's Disease. MS=Multiple Sclerosis p ≤ 0.05 is statistically significant | | | | | | | | |