

## EVALUATION OF INTERVENTION ACCEPTABILITY IN COMMUNITY STUDIES WITH INDIVIDUALS AND DYADS AFFECTED BY DEMENTIA

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Multiple non-pharmacologic interventions for symptom management in community dwelling individuals with dementia have demonstrated effectiveness, but have had limited uptake in practice. Prior reviews have evaluated acceptability of interventions for caregivers, but none have evaluated interventions for care recipients with dementia and dyads. This review synthesized the evidence about intervention acceptability for dyads (individuals with dementia and informal caregivers) and individuals with dementia residing at home. Four databases were searched (PubMed, CINAHL, AgeLine, PsycINFO) using inclusion criteria of: intervention studies, community dwelling individuals with dementia or dyads of care recipients and informal caregivers, non-pharmacologic intervention, evaluation of intervention acceptability. Gray literature and non-English articles were excluded. 173 citations were screened by title and abstract, 38 were reviewed by full text, and 19 studies were included. 18 studies focused on dyads, and 13 different non-pharmacologic intervention types were evaluated across studies. Qualitative (n=3), quantitative (n=8) and mixed methods (n=8) were used to evaluate acceptability. Approaches and measures of acceptability included field notes, behavioral checklists, focus groups, semi-structured interviews, questionnaires, and completion rates of intervention sessions and outcome measures. Although participants' benefit and satisfaction with the interventions were high across studies, variability in definitions of acceptability, the methods and measures used constrain the interpretation and generalizability of findings. Psychometric properties of quantitative questionnaires were not addressed even as the most basic level of face or content validity. To enhance the applicability of non-pharmacologic treatments for this population, future research should emphasize the evaluation of intervention acceptability, as well as effectiveness.

## FROM DEFEAT TO EMPOWERMENT: USER EXPERIENCES FROM A HEALTH PROMOTION INTERVENTION FOR PEOPLE WITH DEMENTIA

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Empowering people with early-stage dementia through the provision of information and support has gained an increasing focus as the number of people with dementia increases worldwide. Health Promotion is a mean to empower the person affected to take an active role in the situation, and taking steps themselves to adjust and cope with the condition. The aim of this study was to explore the experiences of people with early-stage dementia provided with support and information through a 12-week Health Promotion course. Data

comprises separate individual semi-structured interviews with 32 people with dementia after attending the course. For each participant, a carer was also interviewed. Interviews were analysed using systematic text condensation. Four categories emerged from the analysis. These were: (I) bridging the post-diagnostic information gap, (II) promoting healthy behaviours, (III) meeting others with early-stage dementia, and (IV) coming to terms with the diagnosis. The results demonstrated that the intervention was well received by participants; learning about dementia, meeting others in the same situation and focussing on maintaining a healthy lifestyle empowered and motivated participants. The participants' carers found the course booklet especially useful and it improved family communication. In conclusion, a 12-week Health Promotion course has the potential to empower people with dementia to cope with their condition through the provision of information, peer-support, which in turn can improve family communication and ease the process of accepting the diagnosis.

## HARMONY STUDY: PIMAVANSERIN SIGNIFICANTLY PROLONGS TIME TO RELAPSE OF DEMENTIA-RELATED PSYCHOSIS

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Dementia-related psychosis (DRP) is common among patients with Alzheimer's disease (AD), Parkinson's disease (PD), dementia with Lewy bodies (DLB), frontotemporal dementia (FTD), and vascular dementia (VaD) and is associated with poor outcomes. HARMONY (NCT03325556) was a Phase 3, placebo-controlled, randomized, relapse-prevention study evaluating the efficacy and safety of pimavanserin for treating hallucinations and delusions associated with DRP. Patients with dementia and moderate-severe psychosis received open-label (OL) pimavanserin for 12 weeks. Patients with sustained response ( $\geq 30\%$  reduction in Scale for the Assessment of Positive Symptoms hallucinations+delusions Total Score AND Clinical Global Impression-Improvement score of much/very much improved) at Weeks 8 and 12 were randomized 1:1 to continue pimavanserin or receive placebo for up to 26 weeks in the double-blind (DB) period. The primary endpoint was time from randomization to relapse of DRP. 392 patients enrolled. 217 (61.8%) eligible patients experienced sustained response and were randomized. OL response was similar regardless of dementia subtype (randomization rates: 59.8% AD, 71.2% PDD, 71.4% VaD, 45.5% DLB, 50.0% FTD), baseline disease characteristics, age, dementia severity, or previous drug therapy. The study stopped early for superior efficacy when a prespecified interim analysis revealed  $>2.8$ -fold reduction in risk of relapse with pimavanserin (hazard ratio: 0.353; 95% CI: 0.172, 0.727; 1-sided  $p=0.0023$ ). Adverse event rates were low and balanced (OL: 36.2%; DB: 41.0% pimavanserin, 36.6%

placebo). No negative impact on cognition or motor function was observed. The Harmony study demonstrated a robust decrease in hallucinations and delusions and significant maintenance of efficacy with pimavanserin treatment in DRP.

#### INITIAL DERIVATION OF POSITIVE DEMENTIA-RELATED OBSERVATIONAL MEASURES: A DESCRIPTIVE ETHNOGRAPHY

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Person-centered caregiving approaches emphasize efforts to protect and maintain the personhood of people living with dementia (PLWD). The influence on person-centered caregiving approaches on PLWD have predominantly focused on deficit-oriented outcomes, such as absence or reduction of behavioral symptoms. While important to quality of life, the absence of measurable “positive” responses to person-centered caregiving approaches limit opportunities to specify sensitive and meaningful outcome measures that more holistically represent PLWD’s care experiences as more than the absence of a negative outcome. To address these gaps, we conducted a secondary analysis of video-observations of PLWD (N=9) surrounding mealtime cares using a descriptive ethnographic approach. Our objectives were to descriptively summarize specific responsive behaviors demonstrated by PLWD surrounding person-centered caregiving interactions, specifying observable features of these responses and consider their utility in future video-observational research. Findings indicate PLWD contribute both verbal and non-verbal communication surrounding person-centered approaches which can be characterized as conversational (starting conversation, answering or asking questions), expressing preferences (indicating needs and preferences, agreeing or disagreeing, complying with or refusing caregiver requests, permission granting), emotional responses (mirroring caregivers’ emotions, demonstrating emotion e.g. smiling), and reflexive (mirroring of caregiver’s actions), with overlap between categories. Findings suggest that PLWD not only contribute and respond in meaningful ways to person-centered interactions, but also initiate a significant number of these interactions. This study contributes to a growing body of research and advocacy that examines the personhood and abilities of PLWD and establishes the utility of observational data in studying PLWD contributions.

#### LIFE COURSE SOCIOECONOMIC STATUS AND LATER LIFE ALZHEIMER’S DISEASE-RELATED NEUROPATHOLOGICAL LESIONS

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While higher life course socioeconomic status (SES) is associated with lower Alzheimer’s Disease (AD) risk,

relationships with AD-related neuropathological lesions are unclear. We hypothesize that high SES in early, mid and late life will be associated with lower frequency of AD-related pathological lesions. The Rush Memory and Aging Project is a cohort of 2025 people age  $\geq 65$  years from Northeastern Illinois recruited 1997 – 2018; 972 participants died. We created binary variables for Braak stage (0-II versus III-VI), NIA-Reagan score (low likelihood/no AD pathology versus high/intermediate likelihood), presence of microinfarcts and, separately, macroinfarcts, and life course SES based on median for late life (baseline income), midlife (income at age 40 years), and early life (composite of parental education and number of siblings). Logistic regression models adjusted for ages at baseline and death, sex, presence of APOE- $\epsilon 4$  alleles, and separately, vascular factors and education. Of 761 participants with relevant data, 69% were women, and mean ages at baseline and death were 83 + 6 years and 90 + 6 years, respectively. High early life SES was related to lower frequency of AD pathology (OR= 0.69, 95% CI 0.50, 0.96) and macroinfarcts (OR= 0.69, 95% CI 0.51, 0.94). Results were similar when adjusting for vascular factors; adjustment for education modestly attenuated these associations. Mid-life and late life SES were not associated with AD-related neuropathological lesions. High early life SES was related to lower frequency of AD pathology and macroinfarct presence. Environment during early development may influence later life brain aging.

#### OUTCOMES OF PRIMARY CARE FOR PEOPLE WITH DEMENTIA: WHAT’S IMPORTANT?

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People with dementia (PWD) typically receive most of their healthcare in primary care (PC), but neurocognitive disorders can be challenging to recognize, assess, and manage in that setting. As a result, cognitive impairment in older adults is often missed or not addressed until later stages. The result is poor management of comorbid health conditions, increased healthcare utilization, and negative outcomes for the patient and family. Further, strategies for improvement and barriers to high quality PC for PWD have received limited attention. To improve PC for PWD, it is essential to understand what care outcomes should be targeted. To address this gap, we used a qualitative approach to examine potential outcomes of PC from the perspectives of older adults, family caregivers, primary care teams, and geriatrics specialists (n=79) from two Veterans Health Administration healthcare systems. Participants were interviewed individually or in focus groups. A directed content analysis based on the adapted Donabedian model was employed and expanded to fully capture transcript content. Three main categories of outcomes were identified: Personhood (i.e., independence), Physical Health and Safety, and Quality of Life. Regardless