FC24: Discrimination and Stigma Scale Ultra Short for People Living with Dementia (DISCUS-Dementia): Development and Psychometric Validation

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Objectives: This work was aimed at characterizing the experiences of discrimination, and report initial psychometric properties of a new tool to capture these experiences, among a global sample of people living with dementia.

Methods: Data from 704 people living with dementia who took part in a global survey from 33 different countries and territories were analysed. Psychometric properties were examined, including internal consistency and construct validity.

Results: A total of 83% of participants reported discrimination in one or more areas of life, and this was similar across WHO Regions. The exploratory factor analysis factor loadings and scree plot supported a unidimensional structure for the Discrimination and Stigma Scale Ultra Short for People Living with Dementia (DISCUS-Dementia). The instrument demonstrated excellent internal consistency, with most of the construct validity hypotheses being confirmed and qualitative responses demonstrating face validity.

Conclusions: The DISCUS-Dementia performs well with a global sample of people living with dementia. This scale can be integrated into large-scale studies to understand factors associated with stigma and discrimination. It can also provide an opportunity for a structured Discussion around stigma and discrimination experiences important to people living with dementia, as well as planning psychosocial services and initiatives to reduce stigma and discrimination.

FC25: Family Caregivers' Perceptions of Expressed Emotion Toward Dementia Patients: A Qualitative Descriptive Study

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Objectives: This study aims to explore the perceptions of family caregivers regarding their expressed emotions (EE) towards dementia patients and to identify factors associated with high and low EE.

Methods: We conducted qualitative descriptive research through semi-structured interviews with 64 family caregivers of dementia patients, regardless of cohabitation status, from 2021 to 2022. Each caregiver participated in three one-hour interviews over three months. We used the Family Attitude Scale (FAS), a validated 30-item, 5-point Likert scale, to measure EE. Higher scores indicate more critical emotions toward the dementia patient, with a maximum score of120. Based on expert advice and data distribution, we set a cutoff point at 40; scores above 40 indicate high EE, while scores of 40 or below indicate low EE. Interviews focused on the caregivers' challenges, sources of encouragement, and support systems. Transcripts were analyzed using thematic analysis. The study received approval from the Clinical Research Ethics Committee of Osaka University Future Medical Center.

Results: High EE caregivers (scores above 40) reported themes such as: poor pre-existing family relationships, lack of a confidant, severe behavioral and psychological symptoms of dementia (BPSD) in the patient, unemployment,

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low self-esteem, involvement in toileting assistance, inadequate explanations from physicians, and a tendency to reject public support. Additional themes included feelings of frustration and helplessness, lack of emotional support from other family members, and increased caregiver burden due to high care demands. In contrast, low EE caregivers (scores of 40 or below) highlighted themes including: respect for the care recipient, having multiple confidants, mild BPSD in the patient, employment, cooperation from supporters, and a sense of gratitude for caregiving. Further themes identified in this group were effective communication with healthcare professionals, active engagement in caregiver support groups, higher levels of resilience and coping strategies, and a positive outlook on the caregiving role as a meaningful and rewarding experience.

Conclusions: The study identified distinct factors associated with high and low EE among family caregivers of dementia patients. Understanding these factors can help tailor interventions to support caregivers, improve their emotional well-being, and enhance the quality of care for dementia patients.

FC26: Compassion fatigue in informal caregivers

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Objectives: More than 80% of all long-term care services globally are provided by informal caregivers. However, they are often overlooked, underrecognized and insufficiently supported. This study analyses how providing informal care affects mental health and how the negative effects may be prevented or mitigated.

Methods: A cross-sectional study was conducted among informal caregivers in Serbia. Compassion fatigue and compassion satisfaction (CS) were measured with the Professional Quality of Life Scale (ProQOL) version 5. Compassion fatigue is a concept from the formal care setting, a known work-related phenomenon linked to secondary trauma from prolonged work with suffering/ traumatized patients. ProQOL subscales demonstrated good reliability with a Cronbach alpha coefficient of 0.917 on the CS subscale, 0.891 on the burnout (BO) and 0.857 on the Secondary Traumatic Stress (STS) subscale.

Results: A total of 187 informal caregivers participated, with an average age 56.95 ± 12.86 years. 74.9% of the participants were female; the majority married or partnered (62.6%). The median time spent in caregiving was 4 years, ranging from several months to 50 years. The majority of the sample had a moderate compassion satisfaction (72.2%) with moderate levels of compassion fatigue, represented by the BO (67.4%) and STS (64.2%) subscales. Very few participants scored high on CS (3.7%) and high on STS (5.3%). Sex based differences were found for CS and BO domains, with both CS and BO being higher among women ($p = 0.002$ and $p = 0.026$, respectively). BO was found to be higher among singles ($p = 0.049$). Differences were found regarding urban/rural community, with CS being higher among informal caregivers in urban community ($p = 0.041$) and STS being higher in rural community ($p = 0.004$). There was no correlation between age and years spent in caregiving and ProQoL domains.

Conclusions: Over the coming decades, in the absence of a proactive approach, the increasing needs for care will significantly increase the burden of informal caregivers and intensify its consequence on mental health, by pushing moderate levels of burnout and STS towards higher values.