#54 - Barriers and facilitators to implementation of a work-based programme for young onset and early-stage dementia

Presenting Author(s)*
Yoke Boon Tan

Affiliation
Institute of Mental Health, Singapore

Country of residence
Singapore

Objectives/aims

Dementia is characterised by a progressive decline in cognitive domains such as memory, planning, and problem-solving. When such symptoms appear before the age of 65 (i.e., young-onset dementia), individuals may experience difficulties at work which could lead to the involuntary termination of employment. The sudden job loss and associated reduction in social interactions can negatively impact their feelings of self-worth and well-being. Additionally, caregiver burden is especially high among those caring for them. Although dementia-care services are available in the community, they are typically designed for older clients and are inadequate in addressing the different psychosocial needs of younger individuals. The Therapy Through Work for Young onset and Early-Stage dementia (TTW YES) programme was developed by a local community organisation to address this service gap. A key component of the programme was to engage otherwise home-bound YES clients meaningfully through work-based activities. Given the novelty of this intervention, the aim of this study was to use the Consolidated Framework for Implementation Research (CFIR) to understand factors influencing the implementation of this programme. A secondary aim was to evaluate client and caregiver outcomes.

Methods

Constructs from three CFIR domains, namely implementation characteristics, outer setting, and process, were selected for investigation. Interview guides tailored to each stakeholder group and an observation guide were developed based on the CFIR framework. Semi-structured interviews were conducted with 25 key informants who were caregivers, programme staff, and employers. The ethnographic component consisted of 11 on-site observations of clients at work. Interview transcripts and observation notes were later coded deductively. Quantitative data from 38 client-caregiver pairs were also collected at baseline and at every 6-month interval. The Geriatric Depression Scale (GDS) Short Form and EQ-5D Visual

Analogue Scale (VAS) were used to assess depressive symptoms and quality of life respectively in clients, and the Zarit Burden Interview (ZBI) was used to assess caregiver burden. An unconditional linear mixed model was generated for each outcome to examine changes over time. Due to high attrition rate, only data from baseline and the first two follow-ups were analysed.

Main findings

Ten constructs under the three CFIR domains were significant in the implementation of the TTW YES programme. Among these, ‘Relative advantage’ and ‘Adaptability’ were frequently identified as facilitators. The programme’s work-based activities were preferred over centre-based activities in other dementia-care services as the intervention had the added benefit of fostering clients’ sense of contribution to society and preservation of their vocational and motor skills while keeping them connected with others. Work tasks and physical workspaces were adjusted to accommodate clients’ needs, which significantly contributed to the worksites’ smooth onboarding process and allowed for more meaningful engagement of these community-dwelling clients. On the other hand, constructs recurrently identified as barriers were ‘Cost’ and ‘Cosmopolitanism’, owing to the manpower intensiveness, high unanticipated transport fees, and limited number of worksites to meet the intervention’s demand. In particular, the organisation’s staff recounted difficulties in securing partnerships due to upper management of potential companies’ concerns over profits and operational disruptions. Quantitative data suggests that caregiver burden significantly decreased from baseline to T1 after adjusting for the effect of time. However, no significant changes were seen in clients’ depressive symptoms and quality of life across timepoints. These findings provide insight into factors that can enhance the implementation of such work-based community programmes, and practical and systemic issues that may challenge delivery and sustainability of such interventions. Service providers can utilise these findings to better plan and execute similar programmes for persons with young onset or early-stage dementia, to promote their continued community engagement and contribution, improve their well-being and quality of life, and reduce caregiver burden.