The pre-diagnostic phase of young-onset dementia: a scoping review

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Abstract

Background Dementia before the age of 65 is called young-onset dementia (YOD) and affects about 3.9 million people worldwide. Heterogeneity in underlying etiologies lead to clinical variability of first symptoms, which can include cognitive decline, behavioral changes, and language impairment. Younger onset age and prevalence of non-cognitive symptoms poses challenges in recognizing YOD by clinicians, leading to a diagnostic delay of 4-5 years. Recognizing prodromal symptoms is vital for early YOD diagnosis, facilitating access to appropriate services and informal care arrangements. We aim to gain insights into the pre-diagnostic phase of YOD by exploring available literature on presenting symptoms and factors aiding timely diagnosis.

Method Literature search was done across PubMed, Embase, Web of Science, and PsychInfo. Two independent reviewers screened 4,403 titles/abstracts, followed by a full-text review of 556 articles. Standardized data extraction included time to diagnosis, prodromal symptoms, barriers, and facilitators to diagnosis amongst others. Review reporting adheres to PRISMA-ScR guidelines.

Results We included 180 studies of which time to diagnosis was mentioned in 45 studies and ranged from 1 to 13 years. We categorized early symptoms into cognitive, affective, behavioral, vascular, gait, changes in weight or appetite, social and symptoms affecting daily functioning. Prevailing early symptoms reported in 103 studies, were forgetfulness, apathy, depression, learning difficulties, problems with speech, mistakes at work and self-neglect. Common barriers to timely YOD diagnosis included nescience about YOD among clinicians, people with YOD and their caregivers, misdiagnosis, misattribution, and denial while facilitators for early

diagnosis were YOD dedicated diagnostic services, timely referrals, and persistence of follow up in the diagnostic process.

Conclusion This review shows diversity of first symptoms of YOD and identified several barriers and facilitators for timely diagnosing YOD. This information can be used in future research and clinical practice to improve the diagnostic trajectory for people with YOD.