Experiences of people with dementia and their caregivers with post-diagnostic support

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Objectives: Post-diagnostic support (PDS) for people with dementia (PwD) and their caregivers (CG) is key to improving Quality of Life (QoL). However, PDS often does not meet the needs of PwD and CG. The aim of the present study is to provide an in-depth and comprehensive view of early-stage support that takes into account possible differences between experiences of PDS of PwD and CG.

Methods: Cross-sectional survey study for PwD and CG who lived in Australia, Canada, the Netherlands, Poland, and the United Kingdom. PwD were eligible if they were recently diagnosed with dementia (<24 months).

Measurements: Survyes for PwD and survey for CG contained closed questions concerning experiences with the diagnostic process and PDS (information, access to care, and a life and future with dementia). Descriptive statistics and Chi-square tests were used for analyses.

Results: 91 PwD and 299 CG were included. A total of 68.8% of PwD and 66.5% of CG reported that support after the dementia diagnosis did help them deal more efficiently with their concerns. Information and advice yielded high dissatisfaction rates. PwD and CG differ in their experience of support, with a tendency for CG to be more dissatisfied compared to PwD. Results highlight differences across countries in experience of PDS.

Keywords: dementia, post-diagnostic support, informal caregivers