
CONFERENCE ABSTRACT

A comparative analysis of national care pathways for people with dementia living at home in Europe

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Introduction: Care pathways chronologically pinpoint the key steps to be taken throughout a person's care journey. In the case of dementia, the term "care pathway" makes reference to how national systems seek to provide seamless care and treatment from the moment of detection and diagnosis of dementia to end of life. The term also refers to the experiences of people with dementia and their families with such care systems.

Methods: The aim of this study was to collect and compare information about existing national care pathways for people with dementia living at home in Europe. The information was collected via a questionnaire sent to national Alzheimer organisations. 30 countries participated in the study. Questionnaires were completed by the national organisation and, whenever necessary, with the aid of relevant national experts. Organisations were contacted again when necessary to clarify certain issues. The comparative report was sent to all participating organisations for final approval.

Results: This comparative study has collected information on national policies and practices addressing different aspects of the timely diagnosis of dementia and of the post-diagnostic care and support available to individuals with dementia in 30 European countries.

The study provides information about the journeys of individuals from the time they start experiencing a cognitive change to the time they are diagnosed with dementia. It looks at national policies addressing the timely diagnosis of dementia and at what a person who is experiencing cognitive changes needs to do in order to be assessed and diagnosed. It provides information about the role of primary and secondary care and the interplay between them. It also considers the role of the person with dementia in this process, with a particular focus on the disclosure of diagnosis to the person and information about the disease that the person will receive at the time of diagnosis.

Whilst diagnosis is a crucial step, getting a diagnosis is only the first step in the dementia journey. The needs and experiences of receiving and living with a diagnosis of dementia are unique and complex. This study also collected information about the support and care services that are in place to support people to live well with dementia. It provides an overview of how people with dementia and their families get to know about and access the psychosocial support and care available in their country. It covers aspects related to how their support and care

needs are assessed at the time of diagnosis. It also looks at the ongoing needs of people with dementia, how they navigate the care system and the challenges they may face.

Discussion: Findings of this comparative study highlight relevant inequalities in regards to access to specialised care across Europe. These inequalities include differences between countries, but also large regional variations within individual countries in regards to the time and type of access to diagnostic services. This indicates that the place where the individual lives may have an important impact on the pathway to diagnosis and on ongoing monitoring of dementia. An issue of special concern is the limited involvement that people living with dementia may have in diagnosis. A number of people with dementia are still not routinely consulted about relevant decisions relating to their diagnosis, including their desire to be informed about their diagnosis.

This comparative study shows that in some countries psychosocial support after diagnosis is either lacking or underdeveloped. In around one third of the countries, a support worker role has been developed and may facilitate the access and transitions in the care system. Nevertheless, in these countries differences are reported in terms of accessibility to this professional and also in the concrete role and approach that each country has followed. Conversely, where this role does not exist, practices are less consistent and the information and the time at which people with dementia receive information greatly varies. Whilst social workers and community nurses are relevant providers of information, these professionals are often consulted only when care needs arise. This suggests that, often, care and support systems are crisis driven rather than preventive and proactive.

Conclusion: This comparative study outlines the main similarities and differences in the processes that people need to follow to be diagnosed and to access the support and care in these countries. It highlights some of the gaps and main challenges that these individuals may experience. In doing so, the report shows that there is not always a single, linear pathway that may suit every person and every country.

Keywords: national care pathways; dementia; community; diagnosis; post-diagnostic support
