Availability of information on young onset dementia for patients and carers in six European countries

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Abstract

Objectives
To identify information available in six European countries (England, France, Germany, Netherlands, Portugal, Sweden) that addresses the specific needs of people with young onset dementia (YOD) and their carers, and identify gaps.

Methods
Search of websites of organisations with potential interest in dementia. Narrative synthesis and comparative analysis.

Results
21 sources of information were identified (Netherlands 6, England 6, France 3, Germany 2, Portugal 2, Sweden 2); 11 were from voluntary sector organisations. Sources dedicated to YOD were limited (4 websites, 4 books); all other YOD information was sub-entries in generic dementia sources, difficult to locate and with limited coverage of relevant topics. Gaps related to implications of living with YOD in Germany, Portugal and Sweden.

Conclusion
Availability of information varies between countries, some having no dedicated source and incomplete coverage of issues of importance to YOD.

Practical Implications
Information is an important means of supporting carers; their needs change as the condition progresses. A comprehensive resource collating key information is needed so that the issues that differentiate the specific needs of people living with YOD from those of people with dementia in older age are available and easily located.

Keywords
Young onset dementia; Information; European countries
1. Introduction

Dementia is usually associated with ageing and its rising prevalence is explained by increasing longevity [1,2]. Many countries have responded to this major public health concern by implementing strategies on prevention, treatment and support [3]. Young onset dementia (YOD), defined as first symptoms before 65 years of age, is comparatively uncommon, with an estimated prevalence, between 45 and 64 years, of 100 individuals per 100,000 population in Europe, Japan and the United States [4], and an annual incidence of 5 to 20 cases per 100,000 person years [5]. With most European health and social care focussed on older-age dementia, a lack of age appropriate services for YOD has been identified, and there is concern that the needs of YOD are unmet [6,7].

YOD differs from later-onset dementia in a number of aspects, including greater heritability [8]. Atypical Alzheimer’s disease is more common in YOD, presenting through non-memory problems, such as language or visuo-spatial dysfunctions, and impaired executive functioning, organizational and planning skills [9,10]. Similarly, greater frequency of frontotemporal degenerations in YOD produces behavioural changes, for example inappropriate social interactions, lack of empathy, poor motivation and general apathy [11, 12]. With such early symptoms developing gradually, diagnosis is often difficult and delayed. Moreover, the pathophysiological differences between YOD and dementia in older age give rise to different disease trajectories [12] that require specialised treatment and management [13].

YOD presents particular problems with broad social, psychological and familial implications. The growing awareness of genetic factors underlying YOD results in uncertainty about the future among relatives and concern for the next generation. The person diagnosed is forced to retire, while relatives also have to cut working hours to adopt caring roles, thus reducing family income. Children’s situations are disrupted, with some also taking on caring responsibilities [14]. Managing behavioural symptoms in the physically active is challenging, particularly for relatively young carers, who are unprepared for such a role and are facing difficulties accepting and understanding the condition [15,16]. Such changing family dynamics create conflicting priorities that add to the day-to-day stress and problems of coping with the situation [17, 18, 19].

We aimed to identify the availability of information that specifically addressed the particular needs of families living with YOD in six European countries (England, France, Germany, Netherlands, Portugal, Sweden), and highlight gaps. This work formed part of a project that aimed to assess policies and strategies for dementia in the young (Rhapsody), and to develop information resources for carers.

2. Materials and methods

Searches for YOD information for patients and carers were conducted between September and December 2014. Standardised research procedures were maintained via in-person and Skype meetings, teleconferences and email. Ethical approval was not required as no participants were recruited.

Websites of organisations with potential interest in dementia were targeted: national and regional government agencies; professional and provider associations; third sector (voluntary, charity) patient advocacy groups; and pharmaceutical companies. Lists of organisations were developed in all countries with local YOD experts. Lateral searching covered other potential sources.

Entire websites of YOD agencies were included. The YOD-specific content within websites of organisations with broader remits was identified using search terms (dementia, young/er onset, early onset, pre-senile, younger people, working age, carer) applied in local languages. YOD information
was saved for analysis and links to YOD resources were followed. All accessible styles and media forms were relevant, including online text, printed copies (fact sheets, booklets, articles, books) and audio or audio-visual items (recordings, films, DVDs). Eligibility was based on source and content: sources had to be recognised organisations or authorities (government, public agencies, professional or provider organisations, industry, advocacy groups), and content had to be nationally relevant. Independent personal accounts, opinions, output from local meetings and blogs were excluded (content may not have been checked for accuracy).

Details were recorded in an Excel spreadsheet: title, author/agency/publisher, date, format of material, approximate size (pages/length), website address, date accessed. A brief description of YOD content was provided. Each country prepared a report (in English), that included the spreadsheet, overview of material available and signposted information gaps.

Country reports were subject to narrative synthesis and comparative analysis in England, involving individual discussions with countries to clarify understanding and ensure consistency in the items that were included. This process resulted in some materials being dropped. The content descriptions of the retained items were reviewed and evaluated by two independent researchers in order to identify topics covered. These were discussed and refined to define eight key subject areas: general YOD background; types and symptoms; diagnosis; treatment and therapies; social and emotional (family perspectives, loss, bereavement); formal implications (employment, driving, legal, financial); residential (technology, home adaptations for independence, respite and long term care); resources (help and support). This provided a picture of the overall availability of information by country and gaps in coverage. The overview was used to help develop a new online resource for carers. The subtopics included in each of the topic areas are listed in Table 1. Results were verified in each country at each stage of the synthesis.

Table 1

The continued availability of sources was checked in October 2016 and the search was updated to identify new resources.

3. Results

Agencies

Initial searches identified 21 sources: six each in the Netherlands and England, three in France, and two each in Germany, Portugal and Sweden. Two years later, the same sources were still available, although some web addresses had changed and some content had been extended. About half (11/21) the sources were from the third/voluntary sector. No professional associations or pharmaceutical companies provided information. In the Netherlands, information was produced by a group of nursing homes and a tertiary Alzheimer’s Centre collaborating with a University (Table 2).

Table 2

Four dedicated YOD websites were identified, three voluntary sector (Young Dementia UK (England), national Young Dementia Reference Centre in France and Alzheimer’s Society in Portugal) and the tertiary Alzheimer’s Centre / University collaboration in the Netherlands. Four books (two each in England and Netherlands) written for people with YOD and carers were identified from ‘other resources’ sections of websites. All other YOD information was provided as sub-entries within generic dementia sources, including Alzheimer’s Societies in all countries except Sweden, the National Health
Service and Social Care Institute of Excellence in England, public broadcasting channels in the Netherlands, two national government agencies in Sweden, a non-profit organisation producing training materials in Portugal, and a commercial health information service in France. Some sources provided multiple items on YOD. Videos were available in England (2), France (2) and the Netherlands (4). Appendix A lists sources and items.

**Content of materials**

Comprehensive information was provided by single sources in Netherlands, England and France (three websites, and three books). Topic coverage by other sources was piecemeal, but most frequently focused on medical aspects. In Germany, Portugal and Sweden, gaps related particularly to implications of living with YOD such as employment, finance, driving and legal issues (Table 3).

| Table 3 |

4. Discussion and conclusions

4.1. Discussion

Information for patients and carers in the six European countries was found to be variable, with the broadest range and most comprehensive coverage of topics in the Netherlands, followed by England and France. Searches suggested that access to information is less good in Germany, Portugal and Sweden. Overall, the focus was on medical aspects, rather than the implications of living with YOD, even though studies of information needs of carers of people with dementia indicate varied and changing needs, including anxiety related to disease progression, the dying process and psychosocial issues [20, 21, 22, 23]. Guidance on financial and legal matters [21], and help with practical problems and emotional, as well as physical, coping strategies [24,20], are also paramount. Except in Sweden, the voluntary/charity sector plays a major role, while governments and provider organisations (other than in the Netherlands) have limited involvement.

Lack of attention to YOD may reflect its low prevalence compared to other chronic illnesses and the assumption that it is covered within dementia as a whole. Information was easily accessible from organisations dedicated to YOD, but YOD facts on websites with wider remits were often integrated – and lost – within detail on general dementia. Details difficult to locate and, often, they failed to reflect relevant differences between YOD needs and those of older people. Poor internet search pathways to specific YOD information indicate the importance of developing targeted resources while little recognition of specific YOD needs highlights gaps in resources. However, dedicated websites are not necessarily comprehensive, for example, the Alzheimer’s France website provided more varied information on YOD than the French national reference centre on YOD. Websites provide links to resources, which, although helpful, lengthens the search processes.

International information searches were conducted consistently and with rigour. For accuracy and quality, only items produced by recognised bodies was included. Using the internet as the primary resource, however, could have missed other items which would be important for households without internet access (some 20% of European households, 2014 [25]). Items from regional groups were excluded unless they were produced for national dissemination. This may have affected results in Sweden where health care is organised by local municipalities. The picture of information availability reflects a snapshot at one point in time, and increasing awareness of YOD is resulting in an evolving information environment. Some websites were updated in the two years between searches but there
were no significant new resources. Subsequently, however, the Alzheimer’s Society in the UK has produced an eighty page booklet on understanding the YOD diagnosis [26].

4.2. Conclusion

Availability of information for people with YOD and carers is variable across the six European countries in this study. Some countries have no dedicated source making it difficult to locate information. Specific issues differentiating the needs and concerns of people with YOD from those of people who develop older-age dementia are not comprehensively covered.

4.3. Practice implications

Families living with long-term illness seek information as a coping strategy to ease continuous lifestyle and changes and related psychosocial adjustment, for example with role transition and social stigma associated with dementia [27, 23]. In health and social care, information provision is important for enabling self care, thereby reducing demands on formal services, and support for family carers is viewed as an indispensable and effective component of dementia management, providing benefits to patients [28] and carers alike [29, 30]. Hence, European guidelines highlight carer support as an integral part of treatment [31]. A comprehensive resource collating key information is likely to be the most helpful way to fill the information gap for families living with YOD. The RHAPSODY project is developing an online program to support carers of people with YOD [32] and working with patient advocacy groups to optimise uptake. The program is also intended as an information-provision model for other conditions with poorly met needs.
Acknowledgements

RHAPSODY is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND (www.jpnd.eu). France: National Research Agency; Germany: Ministry of Education and Research; The Netherlands: The Netherlands Organisation for Health Research and Development; Portugal: Foundation for Science and Technology; Sweden: The Swedish Research Council; United Kingdom: Economic and Social Research Council.
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