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Young-onset dementia: meeting the information needs of carers

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Abstract

Increased awareness of dementia is associated with its rising prevalence in an ageing population. Young-onset dementia (YOD) is diagnosed when symptoms occur under the age of 65. Although YOD is less common, with an estimated occurrence of 100 people aged 45-64 per 100,000 population, it can have a devastating effect on family members, who face a lack of age-appropriate information and support. This article has two objectives: to describe an international multidisciplinary research project to develop and test an online resource for carers of people diagnosed with YOD and to reflect on the experience of working on the project from the perspective of an early career researcher. The author describes how the international nature of the study, the multidisciplinary context and liaison with participants have helped to consolidate the author's learning and professional development.

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Keywords

carers, dementia, early-onset dementia, families, neurology, patients

Key points

- *There is a lack of age-appropriate services available to meet the psychosocial needs of people with young-onset dementia (YOD) and their carers*
- *Symptoms of YOD develop gradually; diagnosis is difficult and delayed*
- *YOD requires specialised treatment and management*
- *The RHAPSODY project aims to improve care for people with YOD through an online resource for carers*

Introduction

Increased awareness of dementia among the public and health and social care professions is associated with its rising prevalence in an ageing population (World Health Organization (WHO) and Alzheimer's Disease International (ADI) 2012). Well publicised strategies have been promoted for prevention, treatment and support for dementia in older people (Alzheimer Europe 2016). By comparison, young-onset dementia (YOD) is less common and is diagnosed when symptom onset occurs under the age of 65 years. YOD has an estimated prevalence of 100 people per 100,000 population aged 45-64 in Europe, Japan and the US (Harvey et al 2003), and an annual incidence of 5-20 cases per 100,000 person years (Mercy et al 2008). There is a lack of age-appropriate services to meet the multiple psychosocial needs of younger people who are diagnosed with dementia at an age when they have extensive personal, financial and family responsibilities, and those close to them. When the person diagnosed is forced to stop working, relatives also have to reduce their paid working hours to provide care and children's lives are disrupted, particularly when they have to take on care responsibilities (Millenaar et al 2014).

Presentation in YOD differs from memory problems commonly associated with the late-onset condition, and symptoms develop gradually so that diagnosis is difficult and delayed. Alzheimer's disease in people with YOD may present as language or visuospatial dysfunctions or they may have impaired executive functioning, or organisational and planning skills (Koedam et al 2010, Kaiser et al 2012). Changes in behaviour may include inappropriate social interactions, lack of empathy, poor motivation and general apathy, which result from degeneration in the frontotemporal areas of the brain (Kuruppu and Matthews 2013). Differences between YOD and late-onset dementia create different disease prognoses (Sampson et al 2004) and YOD requires specialised treatment and management (Koopmans and Rosness 2014). Managing behavioural symptoms in people who are young, physically strong and active is challenging, particularly for family carers (Arai et al 2007). Changing family dynamics create conflicting priorities that add to the day-to-day stress and problems of coping with the situation (Harris 2009, Svanberg et al 2011, Ducharme et al 2013).

Aim

This article describes a research project investigating the information needs of carers, friends and the families of people diagnosed with YOD, and provides a perspective on working as a health psychologist research fellow on an international and multidisciplinary project.

The RHAPSODY project

The RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young) project is a European initiative (Box 1) to improve care for people with YOD by developing an online information resource for carers. Researchers in six countries, namely England, France, Germany, the Netherlands, Portugal and Sweden, investigated the availability of, and requirements for, information and support for people with YOD and their carers and families with the primary objective of developing and evaluating an online information resource for carers.

Box 1. The RHAPSODY project

RHAPSODY is a joint European Union project supported financially by the following Neurodegenerative Disease Research (JPND) organisations: the National Research Agency, France; the Ministry of Education and Research, Germany; the Netherlands Organisation for Health Research and Development; the Foundation for Science and Technology, Portugal; the Swedish Research Council; the Economic and Social Research Council, the UK. For more details of the project and contributors, go to www.rhapsody-project.eu. For details of JPND, go to www.jpnd.eu

Research work packages

Following the standard approach to organising and planning academic research, the project tasks were defined in ‘work packages’ (WPs) to make best use of the experience and skills of the researchers while enabling consistent collaboration and communication throughout the project. In complex research programmes, the specific aims of each WP build consecutively to contribute to the overall objectives of a project. In the RHAPSODY project, two WPs covered management and coordination in the group and dissemination of findings and external output to interested stakeholders, two focused on evaluating the availability of resources and what information was needed, and two concentrated on developing and evaluating an online information resource. The author reflects on the importance of understanding research protocols in Box 2.

Box 2. Understanding research protocols

Being involved in research provides an opportunity to learn how a protocol works in practice. The combined experience, knowledge and competence of the research team across all aspects of the work is demonstrated in a comprehensive protocol, which is essential for securing research funding. The team will know the protocol thoroughly by the time the project starts, and they will bring academic, clinical and service provision knowledge to its interpretation. Representatives of the patient and public experience around the condition will also have contributed to the development of the protocol.

- The protocol details the background, purpose, method and outcome aims of a piece of research, and is compiled at the outset to map and evaluate an idea
- The protocol describes the work packages (WPs), research methods, roles and responsibilities of team members, schedule and financial details of the project
- Flow charts and timelines summarise written information, providing a visual overview of how WPs focus on different studies that interact and build to meet the ultimate aims

When joining a team, the protocol may seem complicated, but the practical functioning of the protocol is demonstrated as the research process progresses. The first project meetings may be daunting, particularly when everyone seems to speak in acronyms. Thinking in terms of summary flow charts helps to gain an overall understanding. Take notes and read them promptly afterwards to clear up ambiguities: check understanding and queries with a line manager, colleague or reference source as appropriate.

Information resources

Structured research evaluating the international availability of online resources indicated that information on YOD varied across the partner countries, with the most comprehensive availability in the Netherlands followed by England and France (Jones et al 2018). Findings from online searches were analysed according to the type and content of documents. Reports noted an emphasis on medical aspects, with a lack of coherent information on the everyday implications of diagnosis and support for approaches to coping. Difficulty locating information was a problem when short items on YOD were distributed among general guidance on dementia without adequate signposting or links.

Box 3. Roles in research

Lay people who contribute to research, for example as patient and public involvement (PPI) representatives, have different roles compared with participants. The same person cannot occupy both roles as the separate contributions must be independent.

- PPI representatives contribute to ensuring that the work is relevant to those living with the condition
- PPI representatives advise on all aspects of the research, from the idea and design to how the work is carried out and the findings communicated to the public
- Participants take part in studies and provide data for analysis

The researcher role is different from the role of the healthcare professional. For the healthcare professional conducting research, it may be necessary to establish a relationship as researcher in the context of a study and not as a healthcare practitioner

- The healthcare professional engaging with PPI representatives will encounter opinions and experiences that may not be aired during interactions with patients
- Administering questionnaires or conducting interviews with research participants is different from entering a consultation. It is important to differentiate between acquiring rather than providing information and to ensure that participants understand the researcher role. This will be part of preparation and training

Qualitative research into carers’ perspectives demonstrated how little age-appropriate support and how few resources were available. Carers provided an insight into the devastating effect of YOD diagnosis and how their needs were unmet in terms of type, delivery and social contexts of information. Two research methods secured in-depth information: individual interviews and focus groups. These were conducted and recorded, and the data transcribed verbatim in both cases. The different roles in research are discussed in Box 3. Content analysis was used to identify themes in interview data and these themes formed a framework approach as a basis for analysing the focus group data. The ethical considerations of carrying out qualitative research in different countries are discussed in Box 4.

Box 4. Ethical considerations

Ethical review varies across countries. Research in the UK is subject to scrutiny at various levels in the NHS, at academic institutions and in other organisations, such as charities and patient advocacy groups, that may contribute.

- Researchers working where ethical review is not as extensive may underestimate how much time is needed at several stages in a project to complete the ethical process
- In the UK, ethical review involves gaining permission at national and local level, with separate communication for each NHS site
- External researchers have to complete essential checks before being provided with temporary permission to conduct research at NHS sites
- Universities in the UK may have more detailed ethical processes than those in other countries and it is important to explain this to overseas partners in advance

Interviews conducted in the Netherlands highlighted specific unmet support and communication needs, including help with accepting the diagnosis, carers' changing roles, the variable availability of services and a need for tailored care. Focus groups with carers were held in England, France, Germany, Portugal and Sweden to explore how relevant the experiences of the Netherlands' carers were those in other countries. Feedback from the focus groups confirmed the opinions expressed in the interviews and indicated additional aspects needing information and support. These included raising awareness of 'formal' issues, including administrative, statutory, legal and financial aspects that carers faced when circumstances changed when the person with YOD's professional life ends abruptly. Poor coordination and cooperation across health and care services, the lack of age-appropriate support and limited awareness about the existence of YOD were a source of frustration. Planning and contributing to running the two focus groups in England raised awareness of the underlying immense burden of care, but many carers also highlighted positive experiences of support, which was also noted in German focus groups.

Carers responded positively to the prospect of an online resource and welcomed having access to different types of information as and when needed. The challenges a researcher faces when liaising with participants in qualitative research is explored in Box 5.

Box 5. Qualitative research

Qualitative research methods engage participants, individually or in groups, in a safe context for openly sharing experiences and opinions. Liaison with participants in qualitative research provides researchers with privileged contact and involves balancing personal distance with empathy.

- Intense situations often evoke a broad range of emotional responses. Being aware of potentially emotional situations is important, even when a role involves no more than organising interviews or discussions, assisting or meeting and thanking participants
- Advance discussions and ethical processes relating to training, preparation and provision of support are relevant for everyone involved
- Participants' accounts may reveal shocking experiences and responses that are not immediately evident in a consultation context
- First-hand accounts and exchanges among participants in focus groups can bring researchers into direct contact with harsh realities and they need to be prepared for this
- Insight derived from personal contact with participants in qualitative research must be noted. The professional reflection process should recognise the two-way interaction
- The participants are influenced by the researchers. In turn, the researchers interpret not only the information they are given but also the circumstances, emotions, body language and reactions of the participants

Developing the online programme

The online programme was produced in English, French and German and was compiled to meet the information needs expressed by the carers. Written in an accessible style for reading online, the content was edited to include relevant information in each country. Illustrations were included to explain important points and downloadable files were made available. Separate scripts were prepared for video presentations by healthcare experts in YOD and case examples of carers' experiences were represented in videos by actors. The programme opened with an introduction providing a guide to content and how to navigate the seven parts, which covered the topics highlighted in Box 6.

Box 6. The online programme

1. What is young-onset dementia?
2. A medical perspective on young-onset dementia
3. Frequent problems and solutions
4. Dealing with challenging behaviours
5. Family issues
6. How to get help

7. Looking after yourself

Evaluating the programme

A pilot study was conducted to evaluate the programme in England, France and Germany. Informal carers, unpaid family or friends of people who were diagnosed with YOD within the past three years were recruited to test the resource. 20 volunteers from each country were sought through memory clinics in France and Germany, and support organisations in the UK (Alzheimer's Society 2019, YoungDementia UK 2019).

Participants were randomly allocated to Group A, to receive immediate access to the programme, or Group B, to receive access six weeks later. Both groups were provided with six weeks access to test the programme. Participants completed questionnaires at the beginning of the study, after six weeks and after 12 weeks. This provided information from each group before and after testing the programme as well as information after a six week 'waiting list' period for Group B.

This randomised controlled method allows comparison of two similar groups of participants over the same length of time, with one group provided with an intervention, in this study the information resource, and the other group after their usual treatment, access to whatever information and support that was normally available to them. Participants in Group A were not prevented from accessing their usual sources of information or support. In England, participants completed the questionnaires by telephone; in France and Germany they completed them by telephone or in person.

Each country entered responses to the questionnaires in the central German database. The data were processed and analysed in France, with health economics data analysed in England. Researchers in all three countries collaborated on a qualitative analysis of participants' feedback and the findings are being prepared for publication.

Discussion

Overall, the online programme was well received: participants found it easy to use and helpful to have 24-hour access to information on YOD collated in one place. Some carers commented that the information would have been particularly useful immediately after diagnosis while others felt that some aspects were not yet relevant to their circumstances while coping in the early stages of the condition. The combination of written and spoken information was appreciated, and many participants printed the downloadable materials to read separately or to share with other family members or friends.

Working with multidisciplinary practitioners and researchers from different countries offers an invaluable opportunity to hear about healthcare issues that professionals encounter. Practitioners with backgrounds in nursing, general medical practice, psychiatry and psychology contributed opinions on the lack of awareness of YOD. By exchanging personal experiences they highlighted the need for information and support for families coping with diagnosis and shared their frustration at the lack of resources available.

Researchers are in a position of observation. Even though this may not mean literally observing, through researcher-participant interaction, researchers can gain a holistic insight into everyday events and circumstances as they unfold, for example when a relative has to enter residential care or when persuading a young person with dementia to give up driving after an incident. Working with carers who support someone with YOD demonstrates everyday difficulties, such as arranging telephone appointments or being able to have a telephone conversation.

Conclusion

XXXXXXXXXXXXXXXXX However, the RHAPSODY project highlights the need for more information and support for families coping with YOD. Working as a researcher with an international team of experienced healthcare practitioners and academics has given an invaluable opportunity for reflection, which is important for identifying and consolidating learning, and is necessary for continuing professional development. Engaging with research participants brings understanding of holistic aspects of living with a condition; insight and information often become available from unexpected situations and unplanned exchanges. Reflecting on interactions with participants underlines how often health-related events or carer experiences are processed, interpreted or sanitised by the time they are discussed in a health or social care appointment. Being at hand to experience the 'raw' situation leaves a lasting impression that emphasises the valuable contribution and personal cost of participating in research.

Implications for practice

- *It is important to understand information needs and requirements from the perspective of participants*
- *Internationally appropriate information must address cultural differences: the language of delivery for passing on information must match how people expect to interact with local healthcare professionals*
- *Researchers gain a unique insight into everyday circumstances as they unfold*

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