"It’s the One-Size-Fits-All Approach” – Differing Experiences of Formal Dementia Home and Community Care in Ireland

Louise Hopper¹, Rachael Joyce¹, Astrid Stephan², Anja Bieber², Kate Irving³, and Frans R. J. Verhey³

¹School of Nursing and Human Sciences, Dublin City University; ²Institute for Health Care and Nursing Science, Martin-Luther-University Halle-Wittenberg; ³Department of Psychiatry and Neuropsychology, Maastricht University

Background

Many European countries have adopted strategies to promote timely recognition of dementia and the right type and quality of home- and community-based dementia care services seems to allow people with dementia to remain living well at home for longer. Access to formal dementia care varies widely within and across EU countries and research has shown that people with dementia and their informal caregivers experience many difficulties accessing services even when they have a diagnosis of dementia. Also, some available services seem to be under-used and informal caregivers often wait a considerable time before seeking help.

The uptake and utilization of services is a complex process. While psychosocial and cultural factors are widely thought to influence service use decisions, service-related factors are also thought to play an important role.

The Acticare project (www.acticare.eu) is being conducted in 8 countries (DE, IE, IT, NL, NO, PT, SE, UK). It will analyse the pathways to care for people with dementia and their families in an attempt to better understand the reasons for inequalities in access to dementia care services. This first Acticare study explores the personal experiences, and perceived barriers and/or facilitators to accessing dementia care from the perspectives of people with dementia. The results of the Irish group are presented here.

Methods

An exploratory qualitative design with purposive sampling was used. Two focus groups were held with people with dementia who were using, or had previously tried to access, formal dementia services.

- Group 1 took place with older participants who attend a dementia-specific day centre in a central Dublin neighbourhood (n=3; mean age = 83.7).
- Group 2 comprised of younger participants with early onset dementia from urban and rural locations in Ireland (n=4; mean age = 57.3).

Discussions followed a questioning route that had previously been piloted by the German Acticare team. They were tape-recorded, transcribed and analysed using inductive content analysis.

Acknowledgements

This is an EU Joint Programme – Neurogenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND: www.jpnd.eu (Germany: Bundesministerium für Bildung und Forschung (BMBF); Ireland: Health Research Board (HRB); Italy: Italian Ministry of Health; Netherlands: The Netherlands Organisation for Health Research and Development (ZonMW); Norway: The Research Council of Norway; Portugal: Fundação para a Ciência e a Tecnologia (FCT); Sweden: Swedish Research Council (VRI); United Kingdom: Economic and Social Research Council (ESRC)).

Results

Six common themes emerged across the two focus groups:

(1) The Personal Impact of Dementia

Older participants linked functional decline to advancing age, whereas younger participants were keen to stress that there was more to their lives than just their diagnosis of dementia.

(2) Capacity and Rights

All participants expected to remain living at home, independent, and in control of their lives for as long as possible. Younger participants did not want to be forced into unsuitable services and they felt that their ability to advocate for themselves would result in better support in the future.

(3) Service Availability and Acceptability

Two distinctly different experiences with formal services emerged.

Younger narratives focused on barriers to care and experiences were predominately negative.

Positive experiences were more common among older participants who valued opportunities for social interaction, but stressed the need for service-specific transport.

(4) The Impact of Caring on Families

All participants acknowledged the support of family and friends but were concerned about over-burdening younger participants expressly wanted to protect their children.

(5) Education and Awareness

Only the younger participants reflected on their awareness of their condition. They spoke of the lack of information at diagnosis, a lack of knowledge among the general public, and in some GPs.

References