

Rachael Joyce¹, Louise Hopper¹, Frans Verhey², Marjolein de Vugt², Claire Wolfs², Gabriele Meyer³, Robert Woods⁴, Martin Orrell⁵, Anders Wimo⁶, Geir Selbeck⁷, Orazio Zanetti⁸, Manuel Goncalves Pereira⁹ and Kate Irving¹.

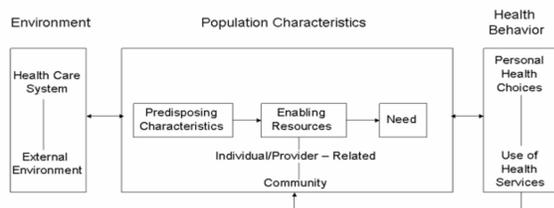
¹School of Nursing and Human Sciences, Dublin City University
²Department of Psychiatry and Neuropsychology, Maastricht University
³Institute for Health Care and Nursing Science, Martin-Luther-University Halle-Wittenberg
⁴Dementia Services Development Centre (DSDC), Bangor University
⁵Department of Mental Health Sciences, University College London
⁶Department of Neurobiology, Care sciences and Society, Karolinska Institutet
⁷National advisory unit on Ageing and Health, Oslo University Hospital
⁸Alzheimer's Research Unit-Memory Clinic, IRCCS
⁹Faculdade de Ciências Médicas da Universidade Nova de Lisboa



Background

- In absence of a cure that can alter the course of Neurodegenerative Disorders, an early diagnosis of dementia is important as it can facilitate improved access to future care, support and treatment, and can empower people with dementia (PwD) and their families to adapt and plan ahead. Timely access to dementia care services is also important for reducing health care costs by postponing nursing home placement, increasing quality of life for PwD, and reducing carer burden.
- Many EU countries have now adopted strategies to promote timely recognition of dementia¹⁻², however, despite these developments, research has revealed that PwD and their carers are not receiving the correct type of services or quality needed, and that they experience much difficulty accessing and working with community care services, even when having a diagnosis of dementia. Furthermore, there is great diversity and inequity among different health care and social care systems related to dementia between and within individual European countries³⁻⁴.
- The Anderson Behavioural Model of Use of Health Service is a theoretical framework that can be used to better understand the complex relationship between needs and service use. The main assumption in this model is that certain factors predispose a patient and their carer to service use, while other factors enable such use, and others determine the need for care, which precedes service use⁵⁻⁶.

The Andersen Model of Health Care Utilization



RM Andersen. Revisiting the behavioral model and access to medical care: does it matter? *J Health Social Behavior* 1995;36:1-10.

- The Anderson model will be used to assess the potential equality of access to and utilisation of services in Europe, by identifying associations between service use and a broad spectrum of predisposing and enabling variables, while controlling for need.

Aim

Actifcare aims to analyse the pathways to care for PwD and their families, in an attempt to better understand the reasons for inequalities in access to healthcare. This project is innovative as it explicitly focuses on the middle stage of dementia, which until now has not received adequate attention in contrast with early stages of dementia or later stages of institutionalisation. Actifcare, therefore will identify best-practice pathways to formal care at a time where there is great potential to impact positively upon short and long term quality of life.

References

- Wolfs, C.A., et al., Empowered or overpowered? Service use, needs, wants and demands in elderly patients with cognitive impairments. *International journal of geriatric psychiatry*, 2010. 25(10): p. 1006-12.
- Verbeek, H., et al., A European study investigating patterns of transition from home care towards institutional dementia care: the protocol of a RightTimePlaceCare study. *BMC public health*, 2012. 12: p. 68.
- Wimo, A., et al., Application of Resource Utilization in Dementia (RUD) instrument in a global setting. *Alzheimer's & dementia : the journal of the Alzheimer's Association*, 2012.
- Logsdon, R.G., Gibbons, L. E., McCurry, S. M., & Teri, L. Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging*, 1999. 5 (1): p. 21-32.
- Andersen, R.M., A behavioral model of families' use of health services., C.f.H.A. Studies, Editor. 1968, University of Chicago: Chicago.
- Bass, D.M. and L.S. Noelker, The influence of family caregivers on elder's use of in-home services: an expanded conceptual framework. *Journal of health and social behavior*, 1987. 28(2): p. 184-96.

Method

DIFFERENT CARE PATHWAYS



- Access pathways to formal care will be investigated using a mixed-method approach
 - Literature review and expert consultation will be used to describe and compare the different pathways across the eight European countries.
 - Qualitative focus group will be conducted with PwD, their carers and health and nursing care professionals, to explore personal experiences of accessing formal care, as well as barriers and facilitators to access. Two to four focus group interviews will be conducted in each country with 10 to 15 participants in each.
 - Semi-structured interviews will be conducted with selected persons (n=3-5 per country) who influence national politics and decision making about formal dementia care in order to further examine barriers and facilitators of timely access to formal dementia care.

- A one year prospective European cohort study will investigate access to and use of formal care services by PwD and their carers, and examine how this relates to their (un)met needs and quality of life. In each participating country, 50 patient/carer dyads will be included (N=400). Assessments will take place at baseline, and after 6 months and 12 months follow-up. Both qualitative and quantitative data will be collected. Quantitative data will include:

ARE CARE NEEDS MET?



- Socio-demographic variables, socio-economic variables and relationship characteristics of the PwD and their carers
- Clinical information regarding cognition, behavioural problems, activities of daily living (ADLs) and (un)met needs
- Economic aspects including service use, quality of life of PwD and their carers, disease-specific health-related quality of life and care-related quality of life

COSTS AND CONSEQUENCES



- A cost-consequences analysis of formal care services utilisation, based on the clinical and economic data assessed in the cohort study, will be performed. In addition the utility of two recently developed patient and carer outcome measures (the ICECAP-O and CarerQol) will be evaluated.

- Cross national comparisons of health care systems, individual pathways to care and cost information will provide insight to develop best practice pathways to formal care, in terms of efficiency and cost effectiveness.



Acknowledgements

This 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 (Germany, Bundesministerium für Bildung und Forschung (BMBF); Ireland, Health Research Board (HRB); Italy, Italian Ministry of Health; Netherlands, The Netherlands Organization 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 (SRC); United Kingdom, Economic and Social Research Council (ESRC)).