Executive Summary: Right Time Place Care Project

Improving Health Services for European Citizens with Dementia: Best Practice Strategies for Transition from Home Care to Long-Term Residential and Nursing Care

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Background

The *RightTimePlaceCare* (RTPC) project was designed to examine approaches to the support of people with dementia (PwD) and their carers in eight European countries. It had a particular focus on the development of best practice strategies for the transition of PwD from home care (HC) to institutional long-term care (ILTC) facilities.

The RTPC Consortium consisted of a multidisciplinary group of researchers from Estonia, Finland, France, Germany, the Netherlands, Spain, Sweden and the United Kingdom (UK). The UK component of the project was undertaken solely in England and was conducted by the Personal Social Services Research Unit (PSSRU) at the University of Manchester. The project ran from January 2010 to September 2013 and had six work packages (WPs): Management; Health Care Structure; Survey; Economic Evaluation; Best Practice; and Dissemination. Some of the main findings are detailed below.

Work Package 2 (Health Care Structure)

WP2 described the structure, process and availability of health and social care in each country, and considered the components of best practice for PwD\(^1,2\). This involved an extensive data collection exercise, including separate focus groups for staff and for informal carers and PwD in each nation.

One hundred and thirty-six PwD/carers and 131 staff participated in the focus group exercises. This included 27 and 23 individuals respectively in the UK. Similar views were expressed across all participant groups and countries. Best practice in dementia care was said to entail:

- Early diagnosis.
- The involvement of a general practitioner and the provision of good quality information throughout the whole care pathway.
- A single point of contact, continuous care from a named professional/key worker and personalised, tailor-made support reflecting the idiosyncratic nature of dementia.
- Emotional support and psychological therapies for PwD *and* their carers.
- Good quality care via specialist multidisciplinary teams.

Further components of best practice identified by the UK groups included\(^3,4\):

- Better awareness of dementia, facilitating early diagnosis and access to support.
- Improved care for PwD in acute hospitals (Dementia training was viewed as an important vehicle for achieving this).
• Access to regular respite in a setting where the PwD is comfortable.
• More flexible and creative services in both community and hospital settings.

Work Package 3 (Survey)

WP3 aimed to identify the factors that influence the decision to enter ILTC in each country. Two groups of PwD and their informal and professional carers were interviewed about their health, quality of life, quality of care, service receipt and carer burden. One group lived in the community and received HC but was judged at risk of care breakdown; the other group had recently entered ILTC. Both groups were followed-up after three months\textsuperscript{5,6,7}.

Description of baseline sample

Baseline interviews were conducted with 2014 PwD and their informal caregivers: 1223 HC recipients and 791 ILTC entrants. No statistically significant differences were found between countries in the age, gender or marital status of the PwD interviewed. However, PwD in Spain were more likely to live alone than in other countries, and PwD in Estonia were more likely to be supported by their grown-up children or other relatives/friends (many of whom were in paid work), than those elsewhere. The amount of help informal carers provided with activities of daily living (ADLs) ranged from 29 hours per month in the Netherlands to 173 in Estonia.

Factors associated with ILTC residence versus living at home

ILTC entrants (n=791) were less likely than HC recipients (n=1223) to be married and to have lived with others prior to ILTC admission. They also had higher comorbidity and worse cognitive and functional status, but displayed fewer neuropsychiatric or depressive symptoms. Greater dependency in ADLs was the only factor significantly associated with ILTC residence in all countries.

Quality of life and quality of care

No statistically significant differences were found between the quality of life of HC recipients and ILTC entrants as assessed by PwD themselves. However, care providers scored ILTC residents’ quality of life more highly than informal carers judged that of PwD living at home. Further, informal carers rated PwD’s quality of life lower than PwD did themselves. Quality of life was rated highest in the Netherlands, UK, Germany and Sweden.

Quality of care indicators suggested PwD living at home had experienced more recent weight loss, pain and depressive symptoms than ILTC entrants. However, ILTC residents reported more pressure sores and use of physical restraints. Considerable variation was found between countries: recent weight loss was most often reported in Sweden (for PwD at home and in ILTC); the proportion of recent ILTC entrants with pressure sores was highest in Estonia and Spain; and the use of physical restraints in ILTC was highest in Spain.
**Informal carer burden**

The majority of informal carers of recent ILTC entrants were their grown-up children, whilst PwD receiving HC were variously supported by their children or spouses. Informal carers of PwD living at home experienced more carer burden than carers of recent ILTC entrants in all countries except France and Spain. The lowest levels of carer burden were reported in the Netherlands.

**Predictors of admission to ILTC**

Of the 1223 PwD receiving HC at baseline, 1097 remained at home three-months later; the other 126 had moved to ILTC. Transfer to ILTC was predicted by: living alone; lower cognitive functioning; more severe neuropsychiatric symptoms; more depressive symptoms; and greater informal carer burden at baseline. Although there was wide variation between countries, carer burden appeared to be the factor most associated with ILTC entry. However, the carers of PwD who made the transition to ILTC experienced significantly less burden at three-month follow-up.

**Work Package 4 (Economic Evaluation)**

WP4 sought to estimate the costs of the care received by PwD living at home and in ILTC based on the service receipt data collected in WP3. Special emphasis was placed on exploring differences in costs across settings and countries, and in identifying the main cost predictors using a comprehensive costs approach.

Overall costs were significantly lower in the HC than the ILTC setting in all countries. On average, ILTC cost €4491 per month - 1.8 times more than HC (€2429 per month). The ratio of costs between settings varied from 1.4 in the UK to 2.4 in Sweden. ILTC costs in the UK (€4151) were lower than average, but HC costs (€2890) were higher. Unsurprisingly, care home costs accounted for the majority of ILTC costs (94% on average). Informal caregiving was the biggest cost element in the HC setting (52% on average). Informal carers in the Netherlands spent approximately 2.7 hours per day on dementia care (ADL and IADL), compared with approximately 7.1 hours in the UK and Estonia. The average cost for informal caregiving was €32.02 per day, ranging from €17.22 per day in the Netherlands to €59.83 per day in the UK.

ADL impairment was the most important cost predictor in most countries. However, severity of neuropsychiatric symptoms was more important in France and Spain. On average, one standard deviation decrease in ADL ability translated into a cost increase of about 22%.

In summary, the results from WP4 suggest that preventing ILTC placement may be cost-reducing for European health systems. However, much depends on the country, the way informal care is costed and the degree of impairment of the PwD. Further, the findings from WP3 suggest that any such shift may have implications for the health and well-being of PwD and their carers.
Work Package 5 (Best Practice)

WP5 was designed to explore whether PwD on the threshold of ILTC entry received the most appropriate care according to professional judgement, and whether, how, and with what consequences the mix of institutional and community services offered by care providers could be improved. A ‘Balance of Care’ approach was employed. This involved five interlinked activities:

1. The baseline sample of 2014 PwD was divided into subgroups on the basis of five characteristics deemed likely to be important in determining the setting and costs of their care: cognition; ADLs; behaviour; living situation; and carer burden.
2. Fourteen anonymous case studies were formulated to exemplify a selection of these subgroups, including those commonly found in both HC and ILTC samples (people empirically identified as on the margins of care).
3. Working in small groups, expert practitioners in each country (162 in total) identified where each subgroup would be most appropriately supported: home, extra care housing, residential or nursing care. For those subgroups for whom care at home or extra care housing was recommended, they also specified the support required.
4. The weekly costs of the community care packages proposed by the experts were estimated and compared with the costs of ILTC placement using a public sector costing approach.
5. The resource implications of providing community care for those ILTC entrants thought to have most potential for diversion to the community were explored drawing on information about the likely annual prevalence of ILTC placement in each country.

The findings suggested that if enhanced community services were available, at least a quarter of PwD currently admitted to ILTC in each country apart from Estonia might be more appropriately supported in the community. However, the proposed community care was not always cheaper than ILTC. The estimated maximum annual resources that might be released for re-investment in the community varied greatly, ranging from €52,000 (Estonia) to €121M (UK) when ILTC was costed as residential care, and €364,000 (Estonia) to €365M (France) when ILTC was costed as nursing home care.

The results indicated that governments seeking to make strategic shifts away from institutional care would face different challenges and opportunities depending on their particular context and culture, but highlighted a number of common prerequisites for service reconfiguration:

- The increased provision of community services necessary to enable vulnerable older people to remain in their own homes including home and day care (either generic or dementia-specific), meal, transport and carer support services.
- The use of standardised multidisciplinary assessments to inform decisions about the care of PwD on the cusp of ILTC entry.
- The provision of intensive care/case management or other arrangements to coordinate care.
- The development of staff skills in the management of challenging behavior.
• The provision of information networks to support front line staff and service planning.

References


9. Tucker S, Sutcliffe C, Saks K, et al. (Submitted) Improving the mix of institutional and community care for older people with dementia: An application of the Balance of Care approach in eight European countries. *Aging and Mental Health*
Work Package 6 (Dissemination)

For a full list of publications from this project, please go to webpages:


http://www.nursing.manchester.ac.uk/pssru/research/ServiceArrangementsandIntegration/RightTimePlaceCare

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Fundació Privada Clinic per la Recerca Biomedica, Hospital Clinic of Barcelona (Spain): Adelaida Zabalegui; Montserrat Navarro; Esther Cabrera; Ester Risco; Carme Alvira; Marta Farre; Susana Miguel.

Gerontôpole, University of Toulouse (France): Maria Soto; Agathe Milhet; Sandrine Sourdet; Sophie Gillette; Bruno Vellas.

Acknowledgements

We are grateful to many people and organisations who have assisted us in this project. In particular we should like to thank DeNDRoN, Pennine Care NHS Foundation Trust, Bury Council, Borough Care Stockport, and Greater Manchester West NHS Foundation Trust.