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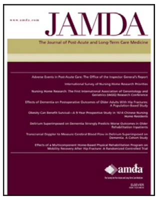

Original Study

What Makes Institutional Long-Term Care the Most Appropriate Setting for People With Dementia? Exploring the Influence of Client Characteristics, Decision-Maker Attributes, and Country in 8 European Nations

Sue Tucker MSc, RMN, RGN [a,*], Christian Brand PhD [a], Caroline Sutcliffe MSc [a], David Challis PhD [a], Kai Saks PhD, MD [b], Hilde Verbeek PhD [c], Esther Cabrera PhD, RN [d], Staffan Karlsson PhD [e], Helena Leino-Kilpi PhD, RN [f], Astrid Stephan MSc, RN [g], Maria E. Soto MD [h] on behalf of the RightTimePlaceCare Consortium[i]

[a] *Personal Social Services Research Unit, University of Manchester, Manchester, United Kingdom*
[b] *Department of Internal Medicine, University of Tartu, Tartu, Estonia*
[c] *Department of Health Services Research, CAPHRI School for Public Health and Primary Care, Maastricht University, Maastricht, The Netherlands*
[d] *School of Health Sciences TecnoCampus, University Pompeu Fabra, Barcelona, Spain*
[e] *Department of Health Sciences, Lund University, Lund, Sweden*
[f] *Department of Nursing Science, University of Turku, and Turku University Hospital, Turku, Finland*
[g] *Faculty of Health, School of Nursing Science, University of Witten/Herdecke, Witten, Germany*
[h] *Geriatrics Department, Gerontôpole, Toulouse University Hospital, INSERM UMR 1027, Toulouse, France*

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ABSTRACT

Objectives: To explore the extent to which client characteristics, decision-maker attributes, and country influence judgments of institutional long-term care (ILTC) appropriateness for people with dementia.

Design, setting, and participants: A total of 161 experts in dementia care from 8 European countries reviewed a series of 14 vignettes representing people with dementia on the cusp of ILTC admission and indicated the most appropriate setting in which to support each case in a simple discrete choice exercise: own home, very sheltered housing, residential home, or nursing home. At least 16 experts participated in each country (Estonia, Finland, France, Germany, the Netherlands, Spain, Sweden, and the United Kingdom).

Measurements: Descriptive statistics were used to characterize the experts and their placement preferences. Logistic regression modeling was used to explore the extent to which the sociodemographic and clinical characteristics of people with dementia, and the profession, workplace, and country of decision-makers were associated with ILTC recommendation.

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[*] Address correspondence to Sue Tucker, MSc, RMN, RGN, Personal Social Services Research Unit, University of Manchester, Crawford House, Booth Street East, Manchester M13 9QS, United Kingdom.

E-mail address: sue.tucker@manchester.ac.uk (S. Tucker).

[i] The RightTimePlaceCare Consortium partners are as follows:

Coordinator: University of Witten/Herdecke (Germany): Gabriele Meyer, PhD, RN, scientific coordinator of the RightTimePlaceCare project; Astrid Stephan, MSc, RN; Anna Renom-Guiteras; Dirk Sauerland, PhD; Ansgar Wübker, PhD; Patrick Bremer.

Consortium Members: Maastricht University (the Netherlands): Jan P.H. Hamers, PhD, RN; Basema Afram, MSc; Hanneke C. Beerens, MSc, RN; Michel H.C. Bleijlevens, PhD, PT; Hilde Verbeek, PhD; Sandra M.G. Zwakhalen, PhD, RN; Dirk Ruwaard, PhD, MD; Ton Ambergen, PhD.

Lund University (Sweden): Ingalill Rahm Hallberg, PhD; Ulla Melin Emilsson, PhD; Staffan Karlsson, PhD; Christina Bokberg, MSc; Connie Lethin, MSc.

University of Manchester (United Kingdom): David Challis, PhD; Caroline Sutcliffe, MSc; David Jolley, PhD; Sue Tucker, MSc, RMN, RGN; Ian Bowns, PhD; Brenda Roe, PhD; Alistair Burns, PhD.

University of Turku (Finland): Helena Leino-Kilpi, PhD, RN; Jaana Koskenniemi, MSc, RN; Riitta Suhonen, PhD, RN; Matti Viitanen, PhD, MD; Seija Arve, PhD, RN; Minna Stolt, PhD; Maija Hupli, PhD, RN.

University of Tartu (Estonia): Kai Saks, PhD, MD; Ene-Margit Tiit, PhD; Jelena Leibur, MD; Katrin Raamat, MA; Angelika Armolik, MA; Teija Tuula Marjatta Toivari, MA, RN.

Fundació Privada Clínic per la Recerca Biomédica, Hospital Clínic of Barcelona (Spain): Adelaida Zabalegui, PhD, RN; Esther Cabrera, PhD, RN (Escuela Superior Ciencias de la Salud TecnoCampus); Ester Risco, MSc, RN; Carme Alvira, MSc, RN; Marta Farre, MSc, RN; Susana Miguel, MSc, RN.

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

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Results: Client characteristics, decision-maker attributes, and country all seemed to play a part in influencing professionals' perceptions of the appropriateness of ILTC for people with dementia. Expert decision-makers were more likely to recommend ILTC for individuals who required help with mobility or had multiple care needs, and appeared to give more weight to carers' than clients' wishes. Community-based social workers were less likely than other professional groups to favor ILTC placement. Experts in Finland, Germany, and the United Kingdom were less likely to recommend ILTC than experts in France, the Netherlands, and Estonia; experts in Sweden and Spain took an intermediate position.

Conclusion: This study provides new understanding of the factors that shape professionals' perceptions of ILTC appropriateness and highlights the need to construct multifaceted models of institutionalization when planning services for people with dementia. It also has several important clinical implications (including flagging interventions that could decrease the need for ILTC), and provides a basis for enhancing professionals' decision-making capabilities (including the greater involvement of clients themselves).

Rising life expectancy is a matter for celebration. Nevertheless, the concomitant increase in the number of older people with dementia brings many challenges for individuals, their families, and professionals. Not least of these is deciding if and when institutional long-term care (ILTC) is appropriate, for although most developed nations aspire to the provision of community support,[1] in light of the progressive nature of dementia, at least three-quarters of older people with dementia will enter ILTC at some point.[2] Such decisions are common, therefore, but also difficult. ILTC can provide high levels of support, alleviating concerns about safety and risk, but also carries high costs, both personal and economic.[2–4]

Although it is widely agreed that older people with dementia should retain responsibility for important decisions about their lives wherever possible, many individuals facing ILTC entry have reduced decision-making capacity.[4,5] In practice, therefore, these decisions are usually made by family members, albeit often in consultation with the person themselves.[2,6] In light of the potentially distressing nature of the subject, however, the possibility of admission is rarely broached in advance.[2,7] Hence, these hugely important and sometimes agonizing judgments are typically made in response to emergencies, such as hospital admission or the death of a spouse.[2,6,8,9] It is thus not surprising that many families seek advice and support from health and social care professionals at this time, nor that the latter's views are deemed particularly influential.[6–8] However, the crisis context of these decisions creates many problems for practitioners. Pressure to alleviate marked carer stress or facilitate rapid hospital discharge means time to consider possible care alternatives is often short, and choices may be based on limited information about individuals' potential functioning, particularly if they are acutely unwell or in a strange environment.[3,4,7,8]

Against this background, it is perhaps understandable that a significant minority of ILTC admissions are deemed inappropriate.[10,11] Nevertheless, although a plethora of work has examined the factors that predict ILTC entry (ie, who *is* admitted to ILTC),[12,13] little is known about professionals' perspectives on the most appropriate use of ILTC (ie, who *is best* supported in ILTC),[14] even though such information would seem to be of great utility to service planners seeking to optimize resource use, and to frontline practitioners, facilitating the provision of advice and transition planning. The study reported here aimed to address this gap, and explored the views of more than 160 experts from 8 European nations on when ILTC for people with dementia is the most appropriate option and the extent to which such judgments are a consequence of individuals' needs, decision-makers' attributes, or country (care culture).

Methods

Design

The research formed part of a European Commission 7th Framework-funded multiphase mixed-methods study: the RightTimePlaceCare project (number 242153). This sought to improve health and social care services for European citizens with dementia at the point of transition to ILTC and was conducted in Estonia (EE), Finland (FI), France (FR), Germany (DE), the Netherlands (NL), Spain (ES), Sweden (SE), and the United Kingdom (UK). Ethical approval for the project as a whole was obtained in each country in accordance with national regulations.

Participants

A variety of experts in dementia care attended 2-hour researcher-led workshops in each country. Experts were defined as people with considerable experience in planning care for people with dementia (eg, case managers, district nurses, geriatric team members, general practitioners, geriatricians, neurologists, and social workers) and could work in any element of the health or social care sector.

Each country had a lead research group who recruited a minimum of 10 ILTC facilities and 3 community providers to participate in the wider study. Recruitment of experts to the workshops followed a snowball approach, whereby researchers invited experts from these services, plus personal contacts, who in turn invited other professionals. The aim was to include all professional disciplines that advised people with dementia about ILTC in real life and at least 15 individuals were required to participate in each country. As the research teams did not invite all the participants themselves, the achieved response rate is difficult to specify. However, evidence suggests there was considerable interest in the study, and the recruitment target was exceeded in every country.

All potential participants were provided with information about the workshops in advance. This was reiterated at the start of each session and attendees were encouraged to ask questions and reminded that they were free to leave at any point. Consent was assumed by attendees' participation in the data collection activity, described in the next section.

Data Collection

Workshops were held in November and December 2012. Each participant was allocated 7 randomly selected vignettes that depicted the needs and situations of people with dementia on the cusp of ILTC