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Long-Term Care Around the Globe

Comparing Palliative Care in Care Homes Across Europe (PACE): Protocol of a Cross-sectional Study of Deceased Residents in 6 EU Countries

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Keywords: Palliative care care home nursing home European quality of end-of-life care

ABSTRACT

Objectives: Although a growing number of older people are dying in care homes, palliative care has developed in these settings only recently. Cross-country representative comparative research hardly exists in this area. As part of a large EU-funded project, we aim to undertake representative comparative research in care homes in Europe, to describe and compare 6 countries in terms of (1) resident outcomes, quality and costs of palliative and end-of-life care; and (2) palliative care structures and staff knowledge and attitudes toward palliative care. We also aim to explore country, facility, staff, patient, and care characteristics related to better outcomes at resident level.

Design and Methods: To obtain a representative nationwide sample, we will conduct a large-scale cross-sectional study of deceased residents in care homes in Belgium, Finland, Italy, the Netherlands, Poland, and the United Kingdom, using proportional stratified random sampling (taking into account region, facility type and bed capacity). In each country, all participating care homes retrospectively report all deaths of residents in and outside the facilities over the previous 3-month period. For each case, structured questionnaires, including validated instruments, are sent to (1) the administrator/manager,
Societies in the European Union (EU) are aging, leading to the need not only to improve health by prevention but also to improve people’s quality of life and enabling them to live and die well. The proportion of the world’s population older than 60 years is expected to double from approximately 11% to 22% between 2000 and 2050. More people will die in late old age following a slow dying course with multiple chronic diseases, years of disability, and complex palliative care needs. The number of people living with dementia worldwide is estimated to double to 65.7 million by 2030 and triple to 115.4 million by 2050. These developments have great clinical, societal, and socioeconomic implications common to all EU countries.

Although health policies in many countries aim to enable people to live in their own homes, many older people will require long-term institutional care at the end of life. A significant proportion of older people also die in care homes (nursing homes or homes for older people or other long-term care facilities); from one-sixth in Italy to one-third in the Netherlands. However, a number of descriptive studies suggest that end-of-life care and quality of dying in these settings can be less than optimal for older people and their families. Symptoms appear underestimated and there is a risk of overtreatment that is continuing life-prolonging, burdensome treatments without knowing individual preferences, or of being transferred to a hospital in the last days of life.

Recent reviews also show there is lack of knowledge about which palliative care systems exist in care homes in Europe and how effective they are in producing high-quality end-of-life care. Although examples of good practice have been documented, palliative care in care homes has not been systematically developed across Europe. Although in some countries palliative care is highly developed in care homes, other countries lack this and rely on the standard care available for these settings. There is no solid evidence about which care system best fulfills the complex needs of older people at the end of life. Most studies are descriptive, small scale, or focused on specific diseases. Also, most existing research identifying the need for improving palliative care in care homes is limited to only one country or region within a country. Thus, we lack large-scale representative and cross-country studies in this area. Additionally, economic evaluations of palliative care are relatively rare. Evidence-based evaluations and comparative EU studies of quality and cost of palliative care are needed to help guide decisions in health care.

PACE (Palliative Care for Older People) is an EU-funded project (2014–2019) that aims to undertake comparative representative research on dying in care homes in Europe. This protocol focuses on one major study within PACE that aims to describe and compare 6 countries (Belgium, Finland, Italy, the Netherlands, Poland, United Kingdom) in terms of resident outcomes, quality and costs of palliative/end-of-life care, palliative care structures/systems, and staff knowledge and attitudes toward palliative care, and aims to unpack the relationship among these structures, processes, and outcomes.

Specific research questions are as follows:

1. To what extent do Belgium, Finland, Italy, the Netherlands, Poland, and the United Kingdom differ in terms of resident outcomes (quality of dying), and quality and costs of palliative/end-of-life care?
2. To what extent do countries differ in terms of palliative care structures/systems and palliative care knowledge and attitudes of staff?
3. To what extent are country, facility, staff, patient, and care characteristics (structures and processes) related to better outcomes (ie, better quality of dying)?

In this article, we outline the research design and methodology developed to answer these research questions. By describing our epidemiological approach, we hope to inform international research methodologies in care homes, in particular on how to perform representative end-of-life care research in these settings, better understand which systems are associated with better outcomes, and use cross-country comparisons to identify areas for improvement in current practice.

Methods

Design

To obtain representative nationwide samples, PACE will conduct a cross-sectional study of deceased residents in care homes in Belgium, Italy, Finland, the Netherlands, Poland, and the United Kingdom, using proportional stratified random sampling. In each country, all participating care homes retrospectively report all deaths of residents (ie, people who are registered as a resident in the facility records) in and outside the facilities over the previous 3-month period. Although a retrospective design may limit the ability to retrieve certain aspects of the treatment histories of deceased patients, it has been identified as the most appropriate design to identify a representative sample of deceased residents. Prognostication on dying in prospective follow-up research is problematic, and all patients cannot be followed until death, resulting in patients living longer being underrepresented. Using a 3-month period limits recall bias and has been successfully tested in previous research.

Additionally, to obtain a representative view of staff knowledge and attitudes regarding palliative care, we will conduct a cross-sectional study of staff (care assistants, nurses) working in the participating homes.

Setting and Participants

Throughout this project, the term “care homes” is used for all “collective institutional settings where care, on-site provision of personal
assistance with activities of daily living, and on-site or off-site provision of nursing and medical care, is provided for older people who live there, 24 hours a day, 7 days a week, for an undefined period of time. Three types of care homes can be differentiated within PACE countries, as shown in Table 1, with a variety of labels used throughout the countries. Across the different countries, there is also quite some variation in organizational funding structures with differential reliance on public, not-for-profit, and private sectors (Figure 1). Data provided in Table 1 and Figure 1 came from a country mapping survey filled in by consortium members, identical to the one used in a previous European survey concerning palliative care development in care homes.

For each deceased resident identified in the participating care homes, structured questionnaires including validated instruments will be sent to the (1) administrator/manager, (2) staff member most involved in care (preferably a nurse), (3) treating physician (general practitioner [GP] or elderly care physician), and (4) a most closely involved relative (family or friend). For each care home participating in the study, a facility questionnaire will be filled in by the administrator/manager. Additionally, all care home staff (care assistants, nurses, head nurses) employed in the care home and on duty at the time the researcher visits the facility will be asked to fill in a separate questionnaire on knowledge and attitudes (not linked to a particular resident).

Sampling and Data Collection Procedures

Sampling procedures will be specified per country. In each country that can use national lists of certified care homes, facilities will be stratified by region (provinces or other large regions depending on the country) and subsequently by facility type (see Table 1) and bed capacity (above and below the median number of beds in care homes in the country) and then sampled randomly to cover the entire country. In addition, in the United Kingdom, the specialist research network for care homes (ENRICH) will be involved in highlighting the study to its members. In Italy, where no public lists of the more than 8000 care homes are available, a previously constructed cluster of care homes interested in participating in research will be used. This convenience sample of care homes includes facilities from 15 of 21 regions, covers the 3 macro regional areas (North, Center, and South) of Italy, and takes into consideration the regional differences in terms of facility size (number of beds) and their characteristics (type, organizational status). A similar strategy was used in previous Italian care home studies including the EU SHELTER project.

Data collection procedures are described in detail in a quality assurance manual to ensure high-quality processes are adhered to. All researchers involved in PACE will be trained extensively by the coordinator to ensure data collection procedures are followed as instructed.

Step 1: A letter introducing the project will be sent to the board of directors/owner/manager asking for voluntary participation (without reimbursement) and telephone or e-mail contact is made.

Step 2: In each participating care home, one contact person for the study (an administrator, head nurse, or manager) will be appointed.

Step 3: The researcher will visit each participating care home and assist the contact person, using structured checklists, in identifying the following:

- all deceased residents (in or outside the care home) over the previous 3 months
- key respondents for each deceased resident (staff member, treating physician, and relative)
- all employed nursing and care staff present or on duty at the day of the visit
- a key person from the care home management (administrator or manager)

The checklists will be filled in by the contact person using the administrative files and consists of a part A containing identifiable names of residents and respondents (to be kept in the facility and never accessible to the researchers), and a part B with unique pseudonimized codes.

Step 4: The structured checklists will be used to prepare the questionnaires and prestamped envelopes, distributed or mailed by the contact person. The questionnaires contain only anonymous questionnaires and prestamped envelopes, and distributed or mailed by the contact person using the administrative files and consists of a part A containing identifiable names of residents and respondents (to be kept in the facility and never accessible to the researchers), and a part B with unique pseudonimized codes.

Step 5: The facility questionnaire will be filled in by a key person of the management during the visit, who may need to consult other staff members to gather all requested information about the facility.

Step 6: The researchers will continuously monitor incoming questionnaires using Excel files. Up to 2 reminders (after 3 weeks) will be sent to physicians, staff, and relatives via the contact person in the facilities, except in Poland and the United Kingdom where relatives will receive 1 reminder (following ethics committees’ requirements).

<table>
<thead>
<tr>
<th>Types of Care Homes in PACE Countries</th>
<th>Type 1 Care Homes With On-Site Care From Physicians, Nurses, Care Assistants</th>
<th>Type 2 Care Homes With On-Site Care From Nurses, Care Assistants, But Off-Site Care From Physicians</th>
<th>Type 3 Care Homes With On-Site Care From Care Assistants, But Off-Site Care Nurses and Physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available (Y) or Not (N)</td>
<td>Label Used</td>
<td>Available (Y) or Not (N)</td>
<td>Label Used</td>
</tr>
<tr>
<td>Belgium</td>
<td>Y</td>
<td>Not applicable</td>
<td>Y</td>
</tr>
<tr>
<td>Finland</td>
<td>Y</td>
<td>Long-term care facilities with 24/7 care</td>
<td>Y</td>
</tr>
<tr>
<td>Italy</td>
<td>Y</td>
<td>Nursing homes (RSA)</td>
<td>Y</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>Y</td>
<td>Nursing homes (“verpleeghuizen”)</td>
<td>Y</td>
</tr>
<tr>
<td>Poland</td>
<td>Y</td>
<td>Care and treatment centers (ZOL)</td>
<td>Y</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>N</td>
<td>Not applicable</td>
<td>Y</td>
</tr>
</tbody>
</table>

*GPs or other elderly care physicians.
number of deaths over a 3-month period across the care homes is at least 4 (Belgium \( n = 5 \), Finland = 4, Italy = 10, Netherlands = 4, Poland = 5, United Kingdom = 4 to 12 depending on type of care home). Estimating the number of people with at least moderate dementia at time of death at 50% and taking into account a nonresponse of 20% for staff but 50% for relatives, PACE aims to include a minimum of 48 care homes (=12×2/2) per country to identify at least 192 deceased residents per country or 1152 deceased residents across countries, 576 with relative responses.

**Data Analyses**

Each country will enter survey data in LimeSurvey, a secure open source survey application. Double data entry is required for 5% of questionnaires (random selection) so as to assess accuracy and to avoid typing errors. If a double entry does not match the original on fewer than 3% of the total number of data entries, the respective partner will be asked to correct the errors. If the number of errors on any given questionnaire exceeds 3% of entries, all questionnaires must be re-entered.

Analyses will focus on describing and comparing countries in terms of resident outcomes and care processes (quality of palliative/end-of-life care) (research question 1), and in terms of palliative care structures/systems at country/facility level, and staff knowledge and attitudes (research question 2). We also aim to identify the characteristics most strongly related to better outcomes for residents, that is, country (eg, palliative care systems), facility (eg, facility type, palliative care policies, and structures), staff (eg, attitudes), patient (eg, functional status, having dementia or not), or care characteristics (perceived quality) (research question 3). As data collected in PACE are nested data (with multiple levels: resident, staff member, facility type, facility, and country), hierarchical analysis techniques will be used such as cluster-robust standard errors or multilevel models as appropriate in various stages of the analyses. An in-depth nonresponse analysis will be performed, as well as missing data analyses.

With regard to cost calculations, we will make an inventory of volumes of care based on the RUD instrument (Resource Utilization in Dementia) and costs of specific treatments in the last month of life. Prices will be calculated preferably by using unit cost prices per country. In the absence of unit cost data from all participating countries, a standard price vector based on the prices of one reference country (eg, the Netherlands) will be used for all. This price vector will be adjusted for differences in price levels across countries using the technique of purchasing power parity, see for example Adang and Borm. The cost calculation will be the product of prices and country-specific volumes of care. To determine whether care homes with higher levels of palliative care development are more efficient than care homes with lower levels and which factors influence the (difference in) efficiency, we will perform a 2-stage approach by using stochastic (bootstrapped) data envelopment analysis (stage 1) and Tobit or truncated regression (stage 2) with potential confounders and case mix variables as covariates (fixed effect). In this way, we ascribe any differences found primarily to systemic differences between countries.

**Ethical and Legal Issues**

All countries obtained ethical approval from the relevant ethics committee in the country or university, except in the Netherlands and Italy where this is not needed because retrospective data of deceased residents are used (ethical committees were informed in these countries to judge whether or not formal ethical approval is needed and a waiver can be provided). The care home directors provide informed consent in writing. The questionnaires sent to the participants in the surveys are anonymous and do not collect identifiable data of
Table 2: Measurements, Units of Analysis, Respondents, and Measurement Instruments in the Study

<table>
<thead>
<tr>
<th>Measurement</th>
<th>Unit of Analysis*</th>
<th>Respondent*</th>
<th>Measurement Instruments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary and secondary outcomes</td>
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</tr>
<tr>
<td>Quality of dying of the residents</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>End-of-Life in Dementia Scales—Comfort assessment while dying (EOLD-CAD) (^{31,32})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Relative</td>
<td>Quality of Dying Long-Term Care (QoD LTC) (^{13})</td>
</tr>
<tr>
<td>Resident’s health-related quality of life in last week of life</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>EuroQol EQ-5D-5L (<a href="http://www.euroqol.org/">http://www.euroqol.org/</a>)</td>
</tr>
<tr>
<td>Relative’s health-related quality of life</td>
<td>Relative</td>
<td>Relative</td>
<td></td>
</tr>
<tr>
<td>Palliative and end-of-life care processes and quality</td>
<td>Deceased resident</td>
<td>Relative</td>
<td>End-of-Life in Dementia Scales—Satisfaction With Care (EOLD-SWC) (^{31,32})</td>
</tr>
<tr>
<td>Quality of palliative care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative care received</td>
<td>Deceased resident</td>
<td>Relative</td>
<td>Country-specific questions depending on the services available (eg, presence of specialist palliative care in care homes)</td>
</tr>
<tr>
<td>Psychosocial interventions and religious/spiritual care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advance care planning and advance directives</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Proposal made by consortium</td>
</tr>
<tr>
<td>Communication with family about the resident</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Proposal made by consortium</td>
</tr>
<tr>
<td>Possibly life-prolonging treatments (artificial food or fluid, ventilation, CPR, blood transfusion, antibiotics etc), hospitalizations treatments discontinued or not initiated</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Proposal made by consortium</td>
</tr>
<tr>
<td>Palliative sedation</td>
<td></td>
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<tr>
<td>Medication of the resident (opioids, antipsychotics, hypnotics, sedatives)</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Proposal made by consortium</td>
</tr>
<tr>
<td>Costs, resource use</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Proposal made by consortium</td>
</tr>
<tr>
<td>Health care resource use last month of life</td>
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<td></td>
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<tr>
<td>Staff knowledge and attitudes toward palliative care</td>
<td></td>
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<tr>
<td>Palliative care knowledge</td>
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<tr>
<td>Relativities toward palliative care</td>
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<tr>
<td>Self-efficacy (staff confidence in providing palliative care)</td>
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<tr>
<td>Interdisciplinary communication and ethical work environment</td>
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<tr>
<td>Patients and family communication and cultural ethical values</td>
<td></td>
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</tr>
<tr>
<td>Structural and facility level characteristics</td>
<td></td>
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</tr>
<tr>
<td>Palliative care systems in a country (the existence of legislation, regulations, and funding mechanisms for palliative care in care homes; whether or not palliative care initiatives are systematically implemented in a country in this setting)</td>
<td>Country</td>
<td>PACE consortium member</td>
<td>Proposal made by consortium</td>
</tr>
<tr>
<td>Facility status (see Figure 1), type (see Table 1), case-mix, size, average length of stay, staffing, and educational level of personnel</td>
<td>Facility</td>
<td>Key management person</td>
<td>Proposal made by consortium</td>
</tr>
<tr>
<td>Palliative care policies in the facility</td>
<td>Facility</td>
<td>Key management person</td>
<td>Based on Belgian survey (^{42})</td>
</tr>
<tr>
<td>Palliative care structures in the facility: Infrastructure and access to palliative care</td>
<td>Facility</td>
<td>Key management person</td>
<td>EU FP7 IMPACT Structural Quality Indicators for palliative care (^{43})</td>
</tr>
<tr>
<td>Clinical and background characteristics</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Comorbidities and cause of death</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Based on Belgian survey in care homes (^{14})</td>
</tr>
<tr>
<td>Expectation of death of resident</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Based on Dutch survey in nursing homes (^{19})</td>
</tr>
<tr>
<td>Functional and cognitive status</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Bedford Alzheimer Nursing Severity Scale (BANS-S) (^{34})</td>
</tr>
<tr>
<td>Clinical judgments on dementia and stage of dementia</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Global Deterioration Scale stage 7 (GDS) (^{35})</td>
</tr>
<tr>
<td>Sentinel events in last month of life (eg, pneumonia, febrile episode, eating or drinking problem) and treatment</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Cognitive Performance Scale (CPS) (^{36})</td>
</tr>
<tr>
<td>Goal of treatment last week of life (curative, life-prolonging, maintaining function, maximizing comfort)</td>
<td>Deceased resident</td>
<td>Physician</td>
<td>Overall clinical judgment As used in the US CASCADE study (^{47})</td>
</tr>
<tr>
<td>Background characteristics (eg, age, gender) and relationship to deceased</td>
<td>Deceased resident</td>
<td>Relative/Physician</td>
<td>Based on care goals literature (^{48})</td>
</tr>
<tr>
<td>Background characteristics of deceased resident (timing of admission, place of death, sociodemographics, socioeconomic status, religion/ethnicity)</td>
<td>Deceased resident</td>
<td>Staff</td>
<td>Proposal made by consortium</td>
</tr>
</tbody>
</table>

(continued on next page)
respondents or residents. All participants take part on a voluntary basis; hence, their written responses will be taken as valid informed consent. To protect residents’ personal data, the lists of those selected for research and the questionnaires are pseudonymized at the LTCF level. The pseudonymization key is kept by the care home directors. The involved researchers will not be informed of the deceased residents’ identity or other personal data that can reveal their identity. Although sensitive and disturbing questions will be avoided in the questionnaires, some respondents (e.g., close relatives) may still become distressed by some questions. Insurance coverage is provided by each participating partner (usually within the frame of the general university insurance). To handle any signs of distress of the relatives receiving the questionnaires, contact details of the researchers will be clearly mentioned, a written protocol for dealing with queries and distress is made available for all researchers involved in data collection, and all researchers will keep a communication log record about the conversations.

**Discussion**

This PACE study will result in the first large-scale international database describing and evaluating quality and costs of palliative care in several types of care homes in Europe, based on representative samples of care homes in 6 EU countries. The PACE methodology described in this protocol can inform other countries on how to initiate analogous representative research in these settings. For so far as we know, such rich data collection integrating structural, system-level data with quality and costs of care, and relating these to resident outcomes, has not been done before. The different countries selected (Belgium, Finland, Italy, the Netherlands, Poland, and the United Kingdom) are a good spread of countries on a number of important parameters: they cover Northern, Western, Eastern, and Southern Europe; include countries with varying histories of economic growth, with different types of health care systems and long-term care systems in particular; and with different levels of development of palliative care. This can inform a large number of other countries that can use this methodology to perform analogous representative research in these complex settings.

An important strength is the measurement of outcomes (e.g., quality of dying) as well as care processes (e.g., quality of care), staff competence and attitudes toward palliative care, and care home structures/characteristics (e.g., facility type, educational level of staff) and costs, making it possible to analyze associations between these different levels and make hypotheses about which palliative care practices might effectuate better outcomes in these settings. The challenge to provide high-quality palliative care in care homes is great in all EU countries. Palliative care was originally developed for and still is mainly provided to patients with end-stage cancer, who typically have short and well-defined end-of-life trajectories, contrary to many older people in care homes, who have needs that fluctuate over a long period of time and trajectories that are difficult to predict. This has resulted in a lack of focus on palliative care in care homes and the question remains what are the optimal systems for palliative care in care homes.

The main limitation of the study is the cross-sectional study design. This will allow description and comparison of countries on a number of characteristics and outcomes, and to find associations between structures, processes, and outcomes of care. However, such data cannot detect cause-and-effect relationships; they can lead only to the formulation of hypotheses about what is needed to achieve better outcomes in care home residents. Another limitation concerns the retrospective design and the use of proxy respondents. Research has shown that the congruence between patients and proxies concerning subjective variables such as symptoms or quality of life is not always high. Additionally, respondents need to recall different elements of the care provided up to three months earlier, hence some memory bias cannot be excluded. However, the use of multiple perspectives in this study (physicians, staff, and relatives) is an important advantage adding to the reliability of the data.

There are also a number of important challenges related to performing representative research in these settings. One of the main difficulties of the study design is the identification of a representative sampling frame for each country. In some countries (e.g., Belgium or Poland) public lists are available of all individual care homes in the country, whereas in other countries (e.g., the Netherlands) a lot of extra effort will be needed to prepare a full list of available facilities in the country, or alternative sampling frames will need to be identified (e.g., Italy). The long distances between care homes in some countries (e.g., Finland, Italy, Poland, United Kingdom) and the lack of strong research tradition in care homes in some countries, makes data collections very time-consuming. The analyses of the results will include an in-depth nonresponse analysis to optimally understand the representativeness of the obtained samples for each country. A particular additional challenge in this comparative research is the large diversity in sizes, organizational structures, funding mechanisms, and populations in care homes in Europe, making cross-country comparisons difficult, with multiple factors and levels needed to take into account.

**Conclusion**

More and more people will live to a very old age in Europe and many of them will develop severe functional and cognitive deficiencies in the last years of life. The number of people dying in care homes after being admitted for a relatively short period is predicted to increase substantially. Hence, this study is timely and aims to optimally inform policy- and decision-makers at international but also at national and regional levels on the current state of affairs of dying in care homes and the possible benefits of different systems of care provision. Using the results of the 6-country study, we hope to provide important recommendations that can also apply to other countries with similar health and long-term care systems as those of the countries involved in PACE. The PACE methodology can also serve as a reference for other countries that wish to initiate large-scale representative end-of-life care research in these settings.
Acknowledgments

We thank all LTCFs and their staff for participating in this project, as well as all physicians and relatives. For Poland, we also acknowledge the Ministry of Science and Higher Education of Poland (decision NK202/7.PR/2014/2 dated November 25, 2014). Finally, we thank the ENRICH network for their support of the UK research team.

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