

IDENTIFYING PUBLISHED STUDIES OF CARE HOME RESEARCH: AN INTERNATIONAL SURVEY OF RESEARCHERS

J.K. BURTON^{1,2}, T.J. QUINN³, A.L. GORDON⁴, A.M.J. MACLULLICH^{2,5},
E.L. REYNISH^{5,6}, S.D. SHENKIN^{2,5}

1. Alzheimer Scotland Dementia Research Centre, University of Edinburgh, United Kingdom; 2. Centre for Cognitive Ageing and Cognitive Epidemiology, University of Edinburgh, United Kingdom; 3. Institute of Cardiovascular and Medical Science, University of Glasgow, United Kingdom; 4. Division of Medical Sciences and Graduate Entry Medicine, University of Nottingham, Derby, United Kingdom; 5. Department of Medicine for the Elderly, NHS Lothian, Edinburgh, United Kingdom; 6. School of Applied Social Science, University of Stirling, United Kingdom.

Corresponding author: Dr Jennifer Kirsty Burton, Room S1642 Geriatric Medicine, University of Edinburgh, Royal Infirmary of Edinburgh, 51 Little France Crescent, Edinburgh, EH16 4SB. Tel: +44 131 242 6481. Fax: +44 131 242 6370, Jenni.Harrison@ed.ac.uk

Abstract: Collating the published research around institutional, long term care is confounded by the differing terminologies used to describe this health-care setting. We aimed to collate the descriptors used by researchers to inform the future development of a 'search filter' (a collection of search terms to help identify relevant records from electronic literature databases). We surveyed international researchers via the Nursing Home Research International Working Group, European Geriatric Medicine Society and published reviewers, achieving at 38% response rate across 21 countries. Our findings identified variation in terminology used by researchers to describe long-term care settings in their country of practice. Nursing home was the most accepted term (96%). 'Homes for the Aged' was selected by 48% of respondents. A range of terms are likely to be necessary to identify all relevant research and these may not be intuitive. We will use these data to help inform development of a search filter.

Key words: Nursing home, long-term care, care home, residential care, survey.

Introduction

Between 2-5% of the older adult population worldwide receive 24-hour care in an institutional long-term setting(1). There is significant variation not only in the names given to these institutions, but also their organisation, funding, staffing and provision of care (2). To allow clinicians and practitioners to understand the similarities and differences in models of care reported in published research, the International Association of Gerontology and Geriatrics and the AMDA foundation (The US Society for Post-Acute and Long-Term Care Medicine) recommend that published research includes detailed description of the care provided, and the staff providing care, to enable readers to interpret whether findings generated overseas translate to their own national setting (3). The established consensus definition for a nursing home is invaluable. However, previously published studies have use a wide range of terminology and authors may continue to use differing terminology that reflects national priorities or incorporate terminology that will be recognisable to local practitioners or policy-makers.

This variation in terminology complicates attempts at comprehensive evidence synthesis. If researchers search electronic literature databases using only the terms preferred in their area, they risk missing relevant publications. Search filters offer a potential solution (4). Search filters are: "collections of search terms designed to retrieve selections of records.....records of research using a specific study design or by topic or by some other feature of the research question" (4). Examples include those developed to identify research

in geriatric medicine (5); renal disease (6) and for specific methodologies such as randomised trials (7).

A search filter to identify long-term care research could be useful, given the marked international variations in terminology used, to support more consistent approaches (and results) when the literature is reviewed (8). Developing a search filter requires a sufficient understanding of terminology required to populate the filter (6). Given the heterogeneity of the terminology for long-term care, this requires consultation with the international community to assure that all relevant terminologies are captured.

Our aim was to identify the terminology used internationally to describe settings where adults receive long-term institutional care when they can no longer live independently in their own homes, to help inform development of a search filter.

Methods

A short questionnaire was piloted with researchers in related fields and lay individuals. Amendments were made to improve consistency in the use of language, the structure and layout to improve readability. The final version was produced in paper (available from the authors on request) and electronic formats, hosted on the web-based platform Survey Monkey (9).

Sampling frame

(i) Attendees at the Nursing Home Research International Working Group (NHRIWG) Meeting in Barcelona (2016)

(ii) Members of the European Geriatric Medical Society (EUGMS) Special Interest Group in Long-Term Care (LTC)

INDICATORS IN NUTRITION SCREENING IN LONG TERM CARE

(iii) Corresponding authors of relevant systematic review protocols registered on PROSPERO[10] or published in PubMed.

Both (i) and (ii) include mixed clinical and academic audiences and source (iii) targeted researchers who have completed or were conducting a systematic review.

The survey was distributed to the EUGMS group by email, paper copies were circulated at the NHRIWG meeting and key authors were emailed individually. The electronic email link was made available for four weeks.

Questionnaire content

A list of terms was generated from: the search strategy from a previous systematic review (8); Cochrane reviews of long-term care; and the indexing terms in PubMed (including Medical Subject Headings (MeSH) terms and keywords) of published systematic reviews. Respondents reported agreement with each term on the list using a five point Likert scale. Additional questions regarding choice of journals and use of databases were asked to inform the search filter development with free-text available for more detailed comments/ explanations.

Respondent case-mix data were collected on:

- Country of practice
- Primary professional qualification
- Prior experience in systematic review
- Perceived usefulness of a search filter
- Contact details for acknowledgement and willingness to be involved in future work

Analyses: All data were entered into IBM SPSS Statistics Version 22. For analysis, the Likert scale was dichotomised into agreement (combining strongly agree and agree) versus disagreement (combining disagree and strongly disagree). Where more than two thirds of responses were in either category this was considered 'good agreement' or 'disagreement'. Responses from individual countries were compared when greater than ten responses were received.

Results

One hundred and five responses were received, 45% from the conference and 55% online. A total of 280 were invited to participate, providing a response rate of 38%.

Responses were received from 21 countries, mostly from the UK (20%), Netherlands (16%) or Australia (12%) (Table 1). Individuals with a primary professional qualification in the field of medicine accounted for the largest group of respondents 39 (37%). Eighty-two (78%) of respondents had previously conducted a systematic review.

Respondents level of agreement with specified terms is described in Table 2. 'Nursing home' had the strongest level of agreement (96%), with 'Medical Home' having the greatest level of disagreement (77%). 'Home for the Aged', a MeSH term used in PubMed, was selected by only 48% of respondents.

'Nursing home' had good agreement in Australia, The Netherlands, UK and USA. 'Care home' had good agreement in The Netherlands and the UK and 'Long-term care' had good agreement there and in the USA. 'Skilled nursing facility' had good agreement in the USA but not from the respondents in the other countries. The terms 'residential facility' and 'residential

Table 1
Country and professional discipline of respondents

County of practice				Professional Discipline	
	N (%)		N (%)		N (%)
UK	21 (20)	Austria	2 (1.9)	Medicine	39 (37.1)
The Netherlands	17 (16.2)	France	2 (1.9)	Nursing	20 (19)
Australia	13 (12.4)	Iceland	2 (1.9)	Social sciences	17 (16.2)
USA	10 (9.5)	Poland	2 (1.9)	Allied Health Professionals	7 (6.7)
Germany	7 (6.7)	Turkey	2 (1.9)	Psychology	4 (3.8)
Canada	5 (4.8)	Indonesia	1 (1.0)	Nutrition	3 (2.9)
Belgium	4 (3.8)	Malta	1 (1.0)	Health Sciences	3 (2.9)
Norway	4 (3.8)	Portugal	1 (1.0)	Pharmacy	2 (1.9)
Ireland	3 (2.9)	Slovenia	1 (1.0)	Other	9 (8.7)
Italy	3 (2.9)	Sweden	1 (1.0)	Total N = 104*	
Spain	3 (2.9)	Total N = 105			

Footnotes: *= Not all respondents completing paper surveys responded to each term, online response was mandatory for each item

THE JOURNAL OF NURSING HOME RESEARCH SCIENCES©

Table 2
Likert scale responses for search terms, ranked based on agreement

Search term	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Total responses received*
Number of responses						
Nursing Home	83	17	2	1	1	104
Long-term Care	58	28	10	6	0	102
Care Home	44	31	10	16	3	104
Residential Home	27	43	14	15	2	101
Residential Facility	25	43	22	12	0	102
Institutional Care	24	35	17	24	3	103
Skilled Nursing Facility	24	22	17	31	9	103
Institutionalisation	19	30	20	23	11	103
Care Facility	16	42	20	22	3	103
Homes for the Aged	14	35	16	28	8	101
Continuing Care	10	23	27	34	9	103
Sub-acute Care	7	9	23	49	15	103
Transitional Care	6	20	23	40	14	103
Post-acute Care	6	18	20	45	14	103
Medical Home	2	7	15	55	24	103

Footnotes: * = Not all respondents completing paper surveys responded to each term, online response was mandatory for each item

home' had good agreement from respondents in Australia and the UK. Free text responses allowed for more detailed comments about the nature and organisation of care provided in specific counties

The vast majority of respondents (93%) stated that a long term care search filter would be useful. The majority (76%) of respondents provided contact details and willingness to assist with next search filter development if needed. MEDLINE/PubMED was the commonest database selected (89%). Respondents also ranked a list of journals they consult for relevant research, and could suggest their own, supplemented by free-text additions. The top three journals consulted were Age and Ageing (71%), Journal of the American Medical Directors Association (68%) and the Journal of the American Geriatrics Society (68%).

Discussion

Our short, focused survey confirmed there is variation in the terminology used to describe long-term care settings and provided information to help develop a search filter. A range of terms are likely to be required to capture all relevant studies and certain descriptors may not be intuitive. Respondents agreed that a search filter would be useful and many were willing to help with validation.

The term 'Nursing home' showed the highest level of agreement, reflecting the progress from the development

of the consensus definition (3). Some terms were favoured in particular regions only, for example 'Care home' a term popular with UK and Netherlands respondents did not feature strongly in North American responses. Researchers may not realise that preferred terms lack international recognition. The MeSH term 'Homes for the Aged' was identified by less than half of respondents, which is likely to be critical when using PubMed/Medline to conduct literature searches.

We are aware of the potential limitations of this work. Selection bias may affect both willingness to participate in the questionnaire, and is likely to select people more likely to support development of a search filter. Our response rate may be an under-estimate due to the overlap between members of the EUGMS Special Interest Group and attendees of the NHRIWG. The data collection methods have led to a relative over-representation of responses from Europe with under-representation of those from the USA and Asia and no responses from Africa or South America. The representation here, however, maps to the international representation in the published English language research literature in long-term care to date, identified in a previous systematic mapping review (11). While engagement from health care professionals was good, we had limited absolute numbers of responses from social care who are crucial in the delivery of care in many countries.

We suggest the most widely agreed terms to assist review authors and will go on to use these to inform development

IDENTIFYING PUBLISHED CARE HOME RESEARCH

of a search filter. The filter will be designed for use in MEDLINE/PubMED. Relevant journals from those suggested by respondents will be hand-searched to develop a resource of publications which are about long-term care settings and those which are not. This searching will be informed by the responses received, mindful of the international variations in terminology. Once a 'gold standard' of long-term care setting research has been developed, the indexing terms and keywords will be tested to help identify those which need to be combined to identify relevant research (12). The psychometric properties of the tool will be tested and sensitive and specific filters will require validation by the long-term care research community before publication and use by researchers (12). This survey will help ensure the search filter has international relevance, encompassing terms and opinions not limited to the UK perspective.

Acknowledgements: With thanks to the organisers of the NHRIWG meeting in Barcelona and to the EUGMS Special Interest Group for LTC for permission to circulate the survey. We are particularly grateful to Professor Yves Rolland for support in dissemination at the meeting. Finally, thanks to those who completed the survey and agreed to be acknowledged: G Abelskamp, W Achterberg, M Baalman, R Backhaus, A Bethel, L Brett, D Bunn, E Campbell, G Caplan, A Castaldo, C Cohen, E Coker, D Collingridge Moore, JC Colmenares, M Cumhuri Izgi, A Curtis, J De Lepeleire, P de Souto Barroto, CJ Dominawez, M Donini Cozenzo, NA Donnelly, R Dwyer, D Faulder, A Fosse, L Garcia, I Gerridzen, E Gorus, D Hamby, B Hanratty, K Hermans, I Hjaltad, M Hoben, J Hockley, BS Husebo, J Jacobson, K Jansen, E Jutkowitz, M Kolšek, W Liu, A Long, M Lovink, M Mann, B Mezuk, J Mitchell, R Möhler, J Morley, M Mousa, B Murphy, P Myint, R Nicot, D O'Neill, D Onolemhurst, R Palm, A Ramos, P Rapaport, A Renom-Guiteras, S Richter, A Rifai, L Robijn, B Roe, S Shenkin, M Smalbrugge, CH Soejono, K Szczerbinska, N Tekin, J van Kooten, M van Leen, MA Vassallo, A Velowik, K Walsh, K Wang, R Watkins, L Weidinger, S Welsh, T Welsh, J Wilbert, C Wöhl, M Woolford & A Zarzeka.

Funding: JKH is supported by a clinical research fellowship from Alzheimer Scotland and The University of Edinburgh Centre for Cognitive Ageing and Cognitive Epidemiology, part of the cross council Lifelong Health and Wellbeing Initiative (MR/L501530/1). AMJM and SDS are members of The University of Edinburgh Centre for Cognitive Ageing and Cognitive Epidemiology, part of the cross council Lifelong Health and Wellbeing Initiative (MR/L501530/1). Funding from the Biotechnology and Biological Sciences Research Council (BBSRC) and Medical Research Council (MRC) is gratefully acknowledged. TJQ is supported by a joint Stroke Association and Chief Scientist Office

Senior Lecturer Fellowship. The funders played no part in the design, analysis or conduct of the review.

Conflict of Interest: The authors declare that they have no competing interests

Ethical Standards: The NHS Research Ethics and Research and Development (R&D) departments were contacted and confirmed that a submission for ethical or R&D approval was not required to distribute and analyse this survey.

References

1. Ribbe MW, Ljunggren G, Steel K, Topinkova E, Hawes C, Ikegami N, et al. Nursing homes in 10 nations: a comparison between countries and settings. *Age and Ageing*. 1997;26 Suppl 2:3-12.
2. Tolson D, Rolland Y, Katz P, Woo J, Morley J, Vellas B. An International Survey of Nursing Homes. *Journal of the American Medical Directors Association*. 2013;14:459-62.
3. Sanford AM, Orrell M, Tolson D, Abbatecola AM, Arai H, Bauer JM, et al. An international definition for "nursing home". *Journal of the American Medical Directors Association*. 2015;16(3):181-4.
4. ISSG Search Filters Resource. What is the ISSG Search Filter Resource? 2016 [cited 2016 16th August]; Available from: <https://sites.google.com/a/york.ac.uk/issg-search-filters-resource/what-is-the-issg-search-filter-resource>.
5. van de Glind EM, van Munster BC, Spijker R, Scholten RJ, Hooft L. Search filters to identify geriatric medicine in Medline. *Journal of the American Medical Informatics Association*. 2012;19(3):468-72.
6. Iansavichus AV, Hildebrand AM, Haynes RB, Wilczynski NL, Levin A, Hemmelgarn BR, et al. High-performance information search filters for CKD content in PubMed, Ovid MEDLINE, and EMBASE. *American Journal of Kidney Diseases*. 2015;65(1):26-32.
7. Glanville JM, Lefebvre C, Miles JN, Camosso-Stepinovic J. How to identify randomized controlled trials in MEDLINE: ten years on. *Journal of the Medical Library Association*. 2006;94(2):130-6.
8. Harrison JK, Walesby KE, Hamilton L, Armstrong C, Starr JM, Reynish EL, et al. Predicting discharge to institutional long-term care following acute hospitalisation: a systematic review & meta-analysis. *Age and Ageing*. 2011;46(4):547-58.
9. Survey Monkey. Welcome to Survey Monkey! 2017 [cited 2017 14th February]; Available from: <https://www.surveymonkey.co.uk/>.
10. NHS National Institute for Health Research, University of York Centre for Reviews and Dissemination. PROSPERO: International prospective register of systematic reviews. 2016 [cited 2016 14th November]; Available from: <https://www.crd.york.ac.uk/PROSPERO/>.
11. Gordon AL, Logan PA, Jones RG, Forrester-Paton C, Mamo JP, Gladman JR. A systematic mapping review of randomized controlled trials (RCTs) in care homes. *BMC Geriatrics*. 2012;12:31.
12. Glanville J, Bayliss S, Booth A, Dundar Y, Fernandes H, Fleeman ND, et al. So many filters, so little time: the development of a search filter appraisal checklist. *Journal of the Medical Library Association*. 2008;96(4):356-61.