Mission (im)possible: Engaging care homes, staff and residents in research studies

Maria Giné-Garriga1,2, Marlene Sandlund3, Javier Jerez-Roig4, Jo Booth1, Dawn A. Skelton1

1School of Health and Life Sciences, Glasgow Caledonian University, UK; 2Department of Physical Activity and Sport Sciences, Faculty of Psychology, Education and Sport Sciences (FPCEE) Blanquerna, Ramon Llull University, Barcelona, Spain; 3Department of Community Medicine and Rehabilitation, Umeå University, Sweden; 4Research group on Methodology, Methods, Models and Outcome of Health and Social Sciences (M3O), Faculty of Health Science and Welfare, University of Vic - Central University of Catalonia (UVIC-UCC). Vic, Spain

Abstract

Objectives: With increasing age the risk of institutionalization increases. To address the problem of under-representation of care homes and their residents in future research studies, we aimed to explore care home staff members’ thoughts on barriers, challenges, facilitators and key aspects of engaging in research studies. Methods: Five staff members from four care homes in Glasgow and Barcelona were interviewed. Transcription of the interviews was completed verbatim and an inductive thematic analysis was conducted to understand the difficulties and challenges they perceive for engaging in research studies. Results: Three themes emerged that encapsulated the staff members’ perspectives. ‘Too much to deal with’ included two subthemes; ‘interested but with support’ encapsulated four subthemes; and ‘on the residents’ terms’ highlighted three subthemes. Staff members showed interest in engaging in research studies if a clear management support accompanied by a whole team approach was evident. The involvement of the resident’s relatives was seen as essential if residents were to be supported to be engaged. Conclusions: Despite the small sample size, the perspectives of staff members, irrespective of country, provided valuable insights for informing researchers on best approaches to maximize care home and resident engagement in research.

Keywords: Care home setting, Older adults, Research engagement, Staff perceptions

Introduction

Improvements in public health care and advances in medical science have significantly extended life expectancy. With increasing age, the risk of institutionalization increases, and one in four older adults will spend time in a care home1. Care-home residents are among the frailest of the population because of their physical dependency2, cognitive impairment3, multimorbidity and polypharmacy2.

Health-based research in this vulnerable population is necessary to try and address the challenges of their health care and ensure that robust, evidence-based service improvements are developed and implemented4. Compared with ageing research overall, research in this sector remains relatively underdeveloped5. This may be partially explained by the complexities associated with recruiting vulnerable people, particularly those with cognitive impairment5, and the genuine ethical concerns for involving this group in research. However, recruitment of vulnerable older adults to research has reported low refusal rates, suggesting their willingness to be involved when given the opportunity7,8. In addition, a recent systematic review showed that older care home residents could be successfully involved in the research process9.

Whilst this is promising, access to care homes to conduct research studies requires the consent of managers and...
providers prior to approaching residents\textsuperscript{10}. Care homes also tend to experience high staff turnover and must contend with pressurised situations, added to evident time constraints. Besides, care home employees are often unfamiliar with research processes. Thus, studies undertaken in care homes may require greater researcher input when compared to similar work in hospitals or in the community\textsuperscript{11}.

To address the problem of under-representation of care homes and their residents in future research studies, we aimed to explore care home staff members’ thoughts on barriers, challenges, facilitators and key aspects of engaging in interventional research studies.

**Materials and methods**

**Participants**

Two staff members from two care homes in Glasgow (one physiotherapist and one manager), and three staff members from two care homes in Barcelona (one care assistant, one nurse and one manager) were interviewed. Ethics approvals were gained from Glasgow Caledonian University and the Faculty of Psychology, Education and Sport Sciences Blanquerna, as part of the GET READY study\textsuperscript{12,13}. All participants signed an informed consent prior to being interviewed.

**Study design**

The interviews aimed at answering the following three research questions: (a) what do you think makes interventional research studies difficult in the care home setting?, (b) what should be done to make participation and recruitment of both care homes and residents easier?, and (c) what are the key aspects for interventions to be implemented in care homes?

**Transcription and data analyses**

Transcription of five recorded interviews was completed verbatim by one researcher (M.G.G.), and an English native lecturer with Catalan and Spanish knowledge subsequently performed spot checks on 50\% of transcripts to ensure accuracy. To allow for the revelation of a shared phenomenon from the data, an inductive thematic analysis was conducted with multiple researchers, following the six steps described by Braun and Clarke\textsuperscript{14}: (1) The reading and re-reading of transcripts to achieve familiarisation with the data (M.G.G.); (2) one researcher (M.G.G.) made initial codes noting interesting features of the data, including quotes perceived as significant; (3) initial codes were then organised into meaningful groups—themes (M.G.G., M.S.); (4) three researchers reviewed, defined and named their themes (M.G.G., M.S., D.A.S.); (5) all other researchers collectively reviewed codes and themes; redefining, renaming, and collated themes when necessary; (6) after discussion, three themes were decided upon that were deemed to best represent the participants’ perspectives. These were then reported back to two staff members originally interviewed to ensure there was agreement with the content of the themes.

**Results**

Interviews lasted between 27 and 38 minutes. Three themes emerged that encapsulated the staff members’ perspectives:

1. **Too much to deal with**

This theme explained the staff members’ perspectives about the difficulties of engaging in research studies in the care home setting. Two subthemes were identified: ‘changing shifts’, and ‘high work load’.

Even though most staff members felt enthusiastic about participating in research, they highlighted the impossibility of coordinating with their colleagues due to changing shifts and high turnover: “It’s hard to communicate with my colleagues when we all work in different shifts that keep changing every week (…). My coordinator moved to another care home last month” (female, care assistant). Staff members agreed that their job required dealing with several tasks with lack of time and human resources: “we all have a lot to do and tasks just keep adding up during the day, I can’t finish the list of tasks with my working hours” (female, nurse).

2. **Interested but with support**

This overarching theme encompassed the staff members’ needs and requirements to get involved in a research study. Four subthemes were found to group their overall perspectives: ‘clear management support’, ‘teamwork – working together’, ‘broadly anchored’, and ‘credit for effort’.

Staff members were concerned about the need for support from their managers, enabling them to deal with the high workload and time constraints: “I want to know every detail of what they [researchers] expect from me and the support I will receive from my boss” (male, physiotherapist). It was important to know the implications and clear tasks to be done, as well as being offered several reminders: “I need clear messages, clear instructions; (…) I feel I’m multitasking all the time so I require constant reminders if a different task is added to my list” (female, nurse).

Staff members also pointed out the importance of getting involved as a team and not as individual workers: “I like being involved in intervention studies but I need time and support from my colleagues” (female, care assistant). Managers agreed on the importance of having all the team equally involved for the success of engaging in any study: “If the study is important to improve our everyday care, all members of staff need to be engaged” (male, manager).

There was also agreement on the importance of involving family members and relatives if an intervention study was to be conducted with residents, thus staff and relatives being broadly anchored towards a common goal: “The best intervention will not succeed if staff members and close
relatives are not convinced” (female, care assistant); “We might be sending contradicting messages to the residents if we don’t talk to their close relatives” (female, manager).

Staff members were also concerned about the importance of their managers acknowledging their participation: “I won’t make extra effort if I don’t get credit for doing so” (female, care assistant); “(…) days are crazy busy around here and I need to know I’ll have some compensation if they want me to get involved” (female, nurse). This was not financial but perhaps removal of some other work task, rather than an addition.

On the residents’ terms

This theme encapsulated the views of staff about engagement of their residents. Three subthemes were identified: ‘involve the resident’, ‘beneficial for residents’, and ‘embedded in everyday routines’.

Staff members suggested that residents like to be involved in decision-making regarding the activities they are offered: “They like it when we ask; we have seen they participate much more” (female, care assistant); “(…) we had a great idea we all thought it would be a success, but then, barely no residents signed up for the activity” (male, physiotherapist). Staff members also pointed out the importance of residents receiving some (health-related) benefits of any intervention delivered within the care home: “I need to be convinced that the study will be of benefit to the care home and the residents (…), only then I will agree to get involved” (male, manager); “Is it useful? Then go ahead” (male, physiotherapist); “Let’s speak the truth: our residents won’t do anything if they don’t see an immediate benefit” (male, manager). Similarly, the importance of the residents’ instructions/implications being simple and flexible was also mentioned: “Most of our residents have a very low functional and cognitive performance (…). We have to include formalization of changes into the care home routines, simplicity of actions, flexibility and use a variety of delivery methods” (female, manager); “At their age, less is more. You won’t be able to change routines unless you introduce small changes in their everyday tasks” (male, physiotherapist). However, staff members mentioned that in some cases residents might not want to engage in any activity and they have to respect their decision: “(…) and they will tell us: I’m too old, I can’t be bothered” (female, care assistant).

Discussion

The perspectives of staff members from two countries provided valuable insights for informing researchers how to approach care homes and inform staff members (managers and employees) about intervention research studies to maximize their engagement. Although it was not a research aim, there were no obvious differences between both countries in these particular questions.

Care home staff emphasized that the most relevant difficulties for research involvement were coordinating with their colleagues due to changing shifts and high turnover, as well as high workload. Time constraints were reported in previous studies, even when the benefits of being involved were perceived as far outweighing the negative aspects.

Staff members showed interest in engaging in research studies if clear management support accompanied by a whole team approach was evident. Previous research had shown that to maximise participation, care home’s organisational culture and human resources need to be supportive. This would, in turn, help coordinate staff members regardless of their shift. The involvement of the resident’s close relatives was seen as essential if residents were to be supported to be engaged. It has been argued that increased family involvement is important to residents and is directly linked to improved quality of life. Family-staff interventions to facilitate communication and the achievement of common goals had also shown potential benefits.

Staff members had a clear opinion on residents being involved in the activities offered. The in-residence model is an emerging model of participatory research which embraces the concept of ‘co-creating’ knowledge between researchers, practitioners and patients (e.g. residents) to enhance motivation and engagement. Staff agreed that residents wanted to perceive immediate benefits, even if they were small and subjective, as shown in previous research.

Despite the small sample size, it was interesting to involve two different countries with different cultural backgrounds. Researchers should be aware of the needs of staff and residents’ demands in order to engage care homes in future research studies.

Funding

This work was supported by the European Commission Horizon 2020 Framework Programme [Reference: 747490 - GET READY] (Principal Investigator: M. Giné-Garriga), and by the Ministry of Education, Culture and Sports of Spain [2018 Jose Castillejo’s mobility grant] (Principal Investigator: J. Jerez-Roig).

Acknowledgements

We wish to acknowledge the voluntary participation of all staff members that were interviewed.

Authors contributions:

M.G.G and D.S. designed and planned the study. M.G.G. and J.J.R. participated in data collection. M.G.G., D.S. and M.S. performed all statistical analyses. J.J.R. and J.B. supervised the data analysis. M.S., J.J.R. and J.B. helped to plan the study. M.G.G. wrote the paper. All authors contributed to revising the paper and approved the final version.
Disclaimer

Prof. Dawn Skelton serves as Co-Editor in Chief in the JFSF. Prof. Javier Jerez-Roig and Prof. Jo Booth are Editorial Board members in the Journal. The manuscript underwent peer review process by independent experts.

References

1. Harwood RH. Do we still need care homes? Age Ageing 2004; 33: 529-530.
2. Gordon AL, Franklin M, Bradshaw L, Logan P, Elliott R, Gladman JRF. Health status of UK care home residents: a cohort study. Age Ageing 2014;43:97–103.
3. Lievesley N, Crosby G, Bowman C, Midwinter E. The Changing Role of Care Homes. London: Bupa and Centre for Policy on Ageing, 2011.
4. Witham MD, George J. Clinical trial design for older people - time for a rethink. Q J Med 2014;107:15–16.
5. Katz PR. An International Perspective on Long Term Care: Focus on Nursing Homes. J Am Med Directors’ Assoc. 2011;12(7):487–492.
6. Zermansky AG, Alldred DP, Petty DR, Raynor DK. Striving to recruit: the difficulties of conducting clinical research on elderly care home residents. J R Soc Med 2007;100:258–261.
7. Sinclair H, Batty JA, Oiu W, Kunadian V. Engaging older patients in cardiovascular research: observational analysis of the ICON-1 study. Open Heart 2016;3:e000436.
8. Wood F, Prout H, Bayer A, Duncan D, Nuttall J, Hood K, et al. Consent, including advanced consent, of older adults to research in care homes: a qualitative study of stakeholders’ views in South Wales. Trials 2013;14:247.
9. Backhouse T, Kenikmann A, Lane K, Penhalte B, Poland F, Killett A. Older care home residents as collaborators or advisors in research: a systematic review. Age Ageing 2016;45(3):337–345.
10. Shepherd V, Nuttall J, Hood K, Butler CC. Setting up a clinical trial in care homes: challenges encountered and recommendations for future research practice. BMC Res Notes 2015;8:306.
11. Goodman C, Baron NL, Machen I, Stevenson E, Evans C, Davies SL, et al. Culture, consent, costs and care homes: enabling older people with dementia to participate in research. Aging Ment Health 2011; 15:475–481.
12. Giné-Garriga M, Sandlund M, Dall PM, Chastin SFM, Pérez S, Skelton DA. A co-created intervention with care home residents and University students following a service-learning methodology to reduce sedentary behaviour: The GET READY project protocol. Journal of Frailty, Sarcopenia and Falls 2018;3:132-137.
13. Giné-Garriga, M., Sandlund, M., Dall, P. M., Chastin, S. F. M., Pérez, S., & Skelton, D. A. (2019). A novel approach to reduce sedentary behaviour in care home residents: The GET READY study utilising service-learning and co-creation. International Journal of Environmental Research and Public Health, 16, E418. doi: 10.3390/ijerph16030418
14. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101.
15. Davies SL, Goodman C, Manthorpe J, Smith A, Carrick N, Iliffe S. Enabling research in care homes: an evaluation of a national network of research ready care homes. BMC Med Res Methodol 2014;14:47.
16. Forster A, Airlie J, Birch K, Cicerò R, Cundill B, Elwood A, et al. Research Exploring Physical Activity in Care Homes (REACH): study protocol for a randomised controlled trial. Trials 2017;18:182.
17. Gaugler JE. Family Involvement in Residential Long-Term Care: A Synthesis and Critical Review. Aging Ment Health 2005;9(2):105–118.
18. Anderson KH, Hobson A, Steiner P, Rodel B. Patients with dementia: involving families to maximize nursing care. J Gerontol Nurs 1992; 18:19–25.
19. Maas ML, Swanson E, Buckwalter KC, Lenth R, Specht JP, et al. Nursing interventions for Alzheimer’s family role trials: Final report (RO INR01689). University of Iowa: Iowa City. 2000.
20. Marshall M, Pagel C, French C, Utley M, Allwood D, Fulop N, et al. Moving improvement research closer to practice: the Researcher-in-Residence model. BMJ Qual Saf 2014;23:801–805.
21. Zubair M, Chadborn NH, Gladman JRF, Dening T, Gordon AL, Goodman C. Using comprehensive geniatric assessment for quality improvements in healthcare of older people in UK care homes: protocol for realist review within Proactive Healthcare of Older People in Care Homes (PEACH) study. BMJ Open 2017;7(10):e017270.