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Devi, R. orcid.org/0000-0003-2834-8597, Haunch, K., Graham, E. et al. (8 more authors) (Accepted: 2025) The uncertainties and questions of care home residents, relatives, and staff as a basis for evidence-based improvement and research. *Age and Ageing*. ISSN 0002-0729 (In Press)

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Title

The uncertainties and questions of care home residents, relatives, and staff as a basis for evidence-based improvement and research.

(Total word count: 2498)

Abstract (250words)

Background

Research in long-term residential care settings (or care homes) for older people should address questions and uncertainties that matter most for those receiving and delivering care. Whether research does this effectively is unclear. In part, because the uncertainties and questions of key stakeholders are unmapped.

Objective

To capture and prioritise the uncertainties of older people living in care homes, their relatives, and staff.

Methods

A three-phase mixed methods study: i) gathering uncertainties, ii) data analysis and iii) prioritisation. Phase one used interviews to gather uncertainties from residents (n=14), relatives (n=10), and staff (n=44). In phase two, uncertainties were coded using thematic inductive analysis, represented as “foreground” (necessitating research) or “background” (not needing research) questions, and a prioritisation tool developed. The tool included optional open-text responses, capturing new questions fitting (and additional detail around) the existing sub-themes. During phase three the prioritisation tool was completed by residents (n=95), relatives (n=85), and staff (n=158).

Results

319 uncertainties were identified: 274 foreground (research-based) and 45 background (fact-based) questions. Six broad and 38 sub-themes were developed. Broad themes included: (1) communal living; (2) health and care services; (3) resident care; (4) residents’ health and well-being; (5) residents’ daily life; and (6) care home staff. Priority sub-themes included: enjoy living with others; dignity and respect; support with emotions; meaningful activities; and recruitment and retention.

Conclusion

This is the first study of care home prioritised uncertainties informed by residents, relatives, and staff. The uncertainty-based questions represent important targets for care home research and practice improvement.

Keywords: research priorities, long term care, care homes, older people, priority setting.

INTRODUCTION

Research can improve care processes and outcomes for older people in health and social care. Generating and using research is a focus in many care systems and for research funders [1]. Finite and scarce human and financial resources mean a pragmatic and moral case for focusing on the questions and topics that matter most to those receiving and delivering care. Explicit and prioritised uncertainties from older people and their advocates represent a meaningful research and practice improvement agenda [2, 3]. Where relevant evidence exists, researcher and practice communities can work together on closing the evidence and practice gap: translating evidence into an accessible language/format, disseminating, and using theories of change to guide the implementation of evidence into practice. Where evidence is absent, researcher and practice communities can work together on addressing gaps in knowledge, conducting studies designed to generate the evidence needed.

Uncertainties can be converted into formal and structured questions. Such uncertainty-based questions are a critical starting point [4], for both searching for evidence and contextualising it for settings in which it is intended to be translated and implemented. Evidence gaps can be targeted by research funders.

Research prioritisation exercises relating to older people are not new. Examples include, “disease groups”: dementia [5]; multimorbidity in later life [6]; older people living with advanced chronic kidney disease [7]; and specific care setting priorities: older people living at home [8] including care homes [9]. Studies also incorporate the perspectives of older people and/or relatives [5, 6, 8], or staff [9], but usually separately. We are not aware of studies that capture resident, relative and staff priorities. We focus on presenting resident, relative, and staff priorities because the relative importance of research and/or practice improvement influences the spread, adoption and sustainability of (research based) innovations [10]. We aimed to produce prioritised uncertainties, represent these as researchable questions, and to present care home residents’, relatives’, and staff perspectives.

METHOD

We conducted a mixed methods study (QUANT|QUAL[11]) with three phases: 1) gathering uncertainties; 2) data analysis and prioritisation survey development; 3) prioritisation. Ethical approval was provided by the (DETAILS REMOVED FOR BLIND REVIEW) Ethics Committee (HREC 18-033) in October 2019.

PHASE 1 – GATHERING UNCERTAINTIES

Residents (n=14), relatives (n=10), and staff (n=44) were opportunistically recruited from 7 care homes in the (DETAILS REMOVED FOR BLIND REVIEW) region, England (see supplementary file, table 2 and 3). Most data were collected in-person (n=65), and 3 interviews were conducted online. Participants took part in one-to-one (n=37) or group (n=31) interviews. Data were gathered during Jan-Mar 2020 (n=29) and Nov 2022-Mar 2023 (n=39). The significant gap in these time periods was due to the impact of the COVID-19 pandemic.

An “uncertainty” was an information deficit expressed in response to open ended questions about visiting, living, and working in care homes (e.g. what helps make your day go well? what is important to you? what would make the care home better?). Interviews were recorded, reviewed, and notes made of uncertainties expressed.

PHASE 2 – DATA ANALYSIS AND PRIORITISATION SURVEY DEVELOPMENT

Uncertainties from phase one were coded inductively into broad thematic categories (by RD, KH, and LG) and organised in Microsoft Excel. Exclusion criteria (see Box 1) were applied to the data (by RD, KH, and LG), duplicates removed, similar items merged, and reasons for exclusion recorded.

Box 1: Eligibility criteria applied to phase one consultation data

Included if data/text:

- contained a question,
- described an uncertainty, with the question implied.

Excluded if data/text:

- did not include a question or a question could not be developed due to missing detail,
- out of project scope (for example, questions about reducing carbon emissions or disease aetiology - e.g. what causes Parkinsons Disease?).

Questions were developed from the included data. Because different questions merit different kinds of knowledge and processing to be reliably answered [12], we categorised questions as either “background” (fact-based) or “foreground” (research-based) [13]. We had successfully used this approach when understanding the uncertainties of care home staff during the COVID-19 pandemic. [14].

Background (fact-based) questions need specific, concrete, information to answer them. Information is usually contextualised. Examples included not knowing how to administer a prescribed medication (needing medication charts) or how to access training and guidance.

Foreground (research-based) questions merit evidence-based “guidance” or direction (combined with a degree of judgement) for resolution. They tend towards greater complexity and centre on understanding *how* or *why* something occurs, determining best practice, or exploring innovations in care. Examples included, "what is the most effective intervention to reduce resident falls?" or "how can we improve residents' mental well-being through activities?". Such information deficits required secondary or primary research evidence for reliable and trustworthy resolution, or to surface “known unknowns” [15].

Questions represented 6 broad and 38 sub-themes (see results section) and these were developed into a prioritisation survey instrument. Alongside biographical data collection, we randomly presented uncertainty sub-themes within each of the six broad themes. Participants chose up to two sub themes from each section they felt were “most important and could be improved”. The survey included optional open text boxes where participants could provide relevant information about the sub-theme(s) selected. The survey tool was sense checked by a panel of five care home relatives who recommended minor language and formatting changes.

PHASE 3 – PRIORITISING UNCERTAINTIES

After pilot testing the survey in one care home in (DETAILS REMOVED FOR BLIND REVIEW) (England), we asked care homes in Scotland (n=20), and southern (n=2 DETAILS REMOVED FOR BLIND REVIEW) and northern (n=8 DETAILS REMOVED FOR BLIND REVIEW) areas of England to prioritise uncertainties (see supplementary file, table 2). Three hundred and thirty-four participants responded: residents (n=95), relatives (n=85), and staff (n=158) (see supplementary file, table 3). To maximise participation, we offered paper (n=296 responses), and online (n=38 responses) versions. Most residents (n=92) were supported to complete the survey by care home or research staff. Paper and online data were combined using Online-surveys [16]. Ten percent of responses were checked for coding accuracy by a second researcher.

The sub-themes most frequently selected were treated as the highest priority. Open text responses were analysed using deductive thematic analysis. The purpose was to capture a) new questions, fitting the existing sub-themes, and not identified in phase one, and b) to provide additional detail and refinement to the questions which had been already identified in phase one.

RESULTS

Recruitment, data collection, and uncertainty frequencies are summarised in Figure 1. In total, 319 uncertainties were identified (n=176 in phase one and n=143 in phase three). Foreground questions made up 86% of the uncertainties (n= 274), with the remaining 14% (n=45) constituting background questions (see supplementary file, table 4 and 5).

Six broad themes were generated in phase one: communal living; health and care services; resident care; resident health and well-being; residents’ daily lives; care home staff. Within these broad themes, 38 sub-themes were generated. Figure 2 summarises the type and number of questions in the broad themes. Figure 3 summarises the sub-theme question frequencies.

Prioritised questions and sub-themes most frequently selected (collectively and by participant group) are presented in Table 1. Collectively prioritised sub-themes included: residents enjoying living together; resident dignity and respect; supporting residents with emotions; activities for residents; and staff recruitment and retention. ‘Activities for residents’ was the sub-theme identified most important by each group.

Figure 1: summary of participant recruitment, data collection, and uncertainties

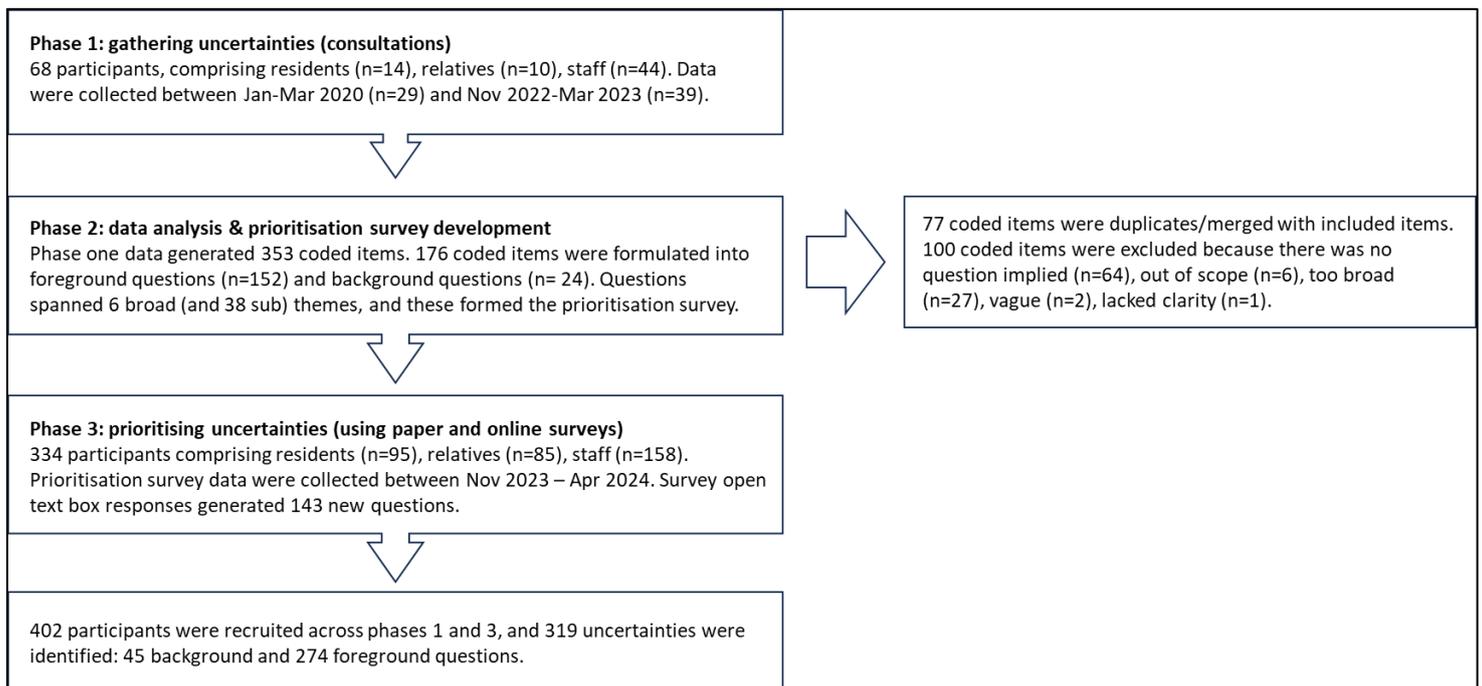


Figure 2: Number of foreground and background questions raised across the broad themes

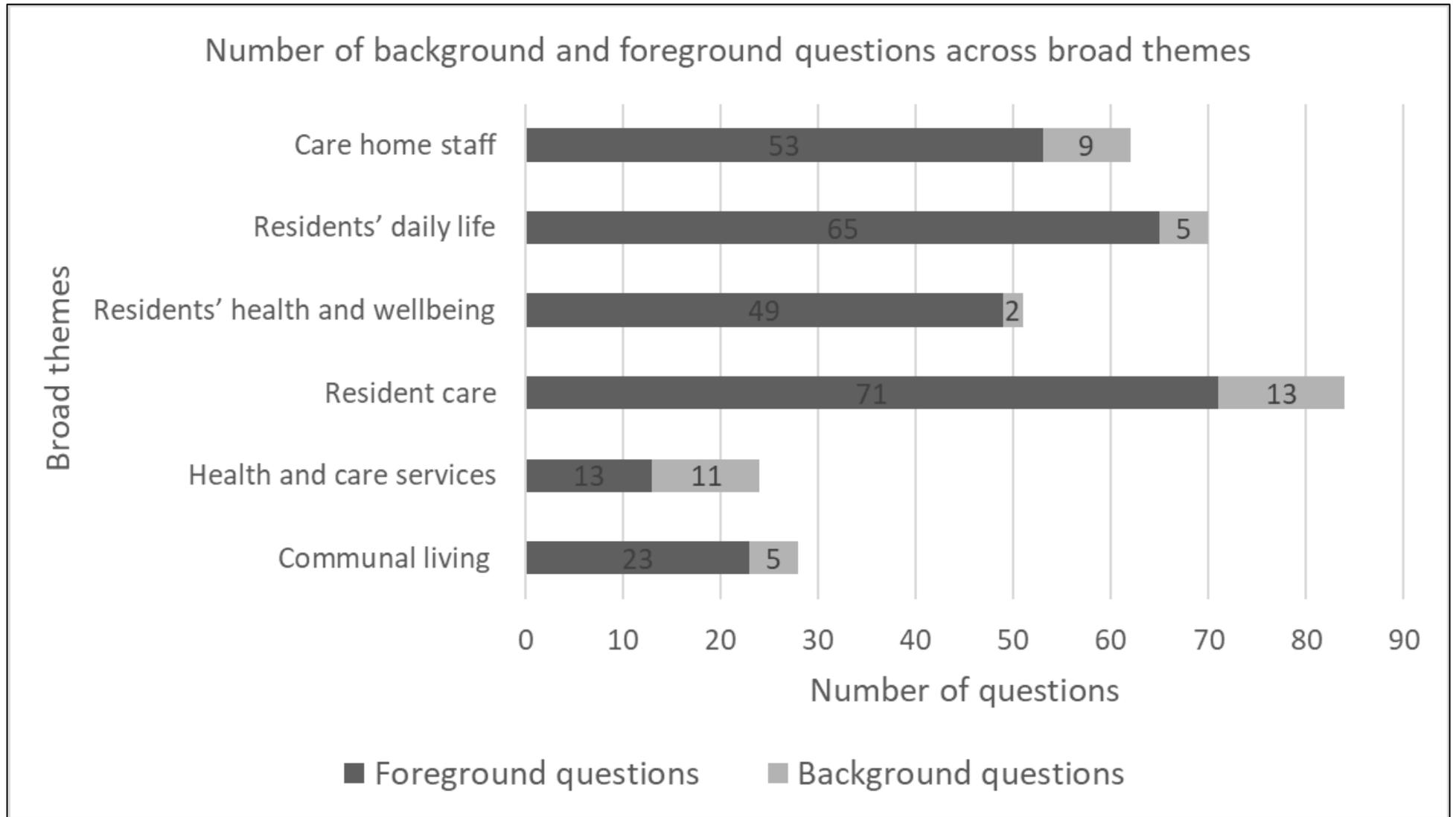


Figure 3: Number of questions raised across sub-themes

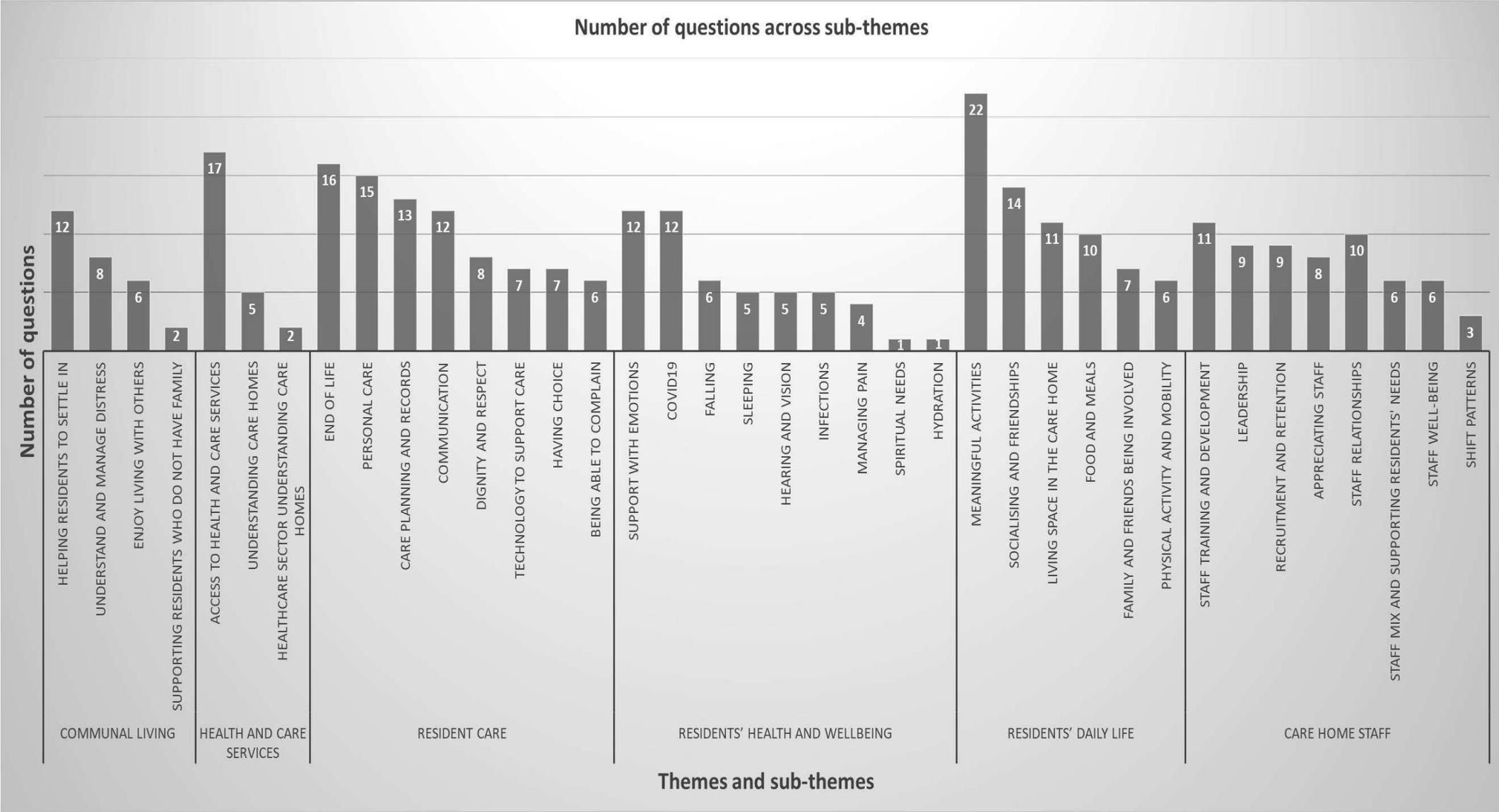


Table 1: prioritisation survey findings (sub-themes prioritised by each participant group shown with shaded cells)

PRIORITY AREAS	Relatives (N=81)		Residents (N=95)		Staff (N=158)		All (N=334)	
	Frequency*	Proportion (%)**	Frequency*	Proportion (%)**	Frequency*	Proportion (%)**	Frequency*	Proportion (%)
COMMUNAL LIVING								
Enjoy living with others	29	36	44	46	39	25	112	34
Understand and manage distress	23	28	22	23	56	35	101	30
Supporting residents who do not have family	12	15	14	15	45	28	71	21
Helping residents to settle in	19	23	15	16	35	22	69	21
HEALTH AND CARE SERVICES								
Understanding care homes	21	26	27	28	66	42	114	34
Access to health and care services	23	28	39	41	46	29	108	32
Healthcare sector understanding care homes	33	41	19	20	40	25	92	28
RESIDENT CARE								
Dignity and respect	41	51	31	33	92	58	164	49
Having choice	22	27	46	48	61	39	129	39
Communication	26	32	17	18	52	33	95	28
Care planning and records	21	26	5	5	34	22	60	18
Personal care	18	22	21	22	17	11	56	17
End of life	9	11	13	14	25	16	47	14
Technology to support care	9	11	23	24	15	9	47	14
Being able to complain	9	11	10	11	12	8	31	9
RESIDENTS' HEALTH AND WELLBEING								
Support with emotions	35	43	25	26	86	54	146	44
Hydration	32	40	18	19	55	35	105	31
Falling	18	22	33	35	45	28	96	29
Hearing and vision	22	27	24	25	33	21	79	24
Managing pain	15	19	18	19	35	22	68	20
Spiritual needs	9	11	11	12	21	13	41	12
Infections	11	14	5	5	22	15	38	11

Sleeping	6	7	23	24	6	4	35	10
COVID19	1	1	5	5	3	2	9	3
RESIDENTS' DAILY LIFE								
Meaningful activities	38	47	42	44	79	50	159	48
Physical activity and mobility	37	46	30	32	63	40	130	39
Food and meals	30	37	33	35	48	30	111	33
Socialising and friendships	23	28	34	36	41	26	98	29
Family and friends being involved	11	14	17	18	49	31	77	23
Living space in the care home	15	19	20	21	27	17	62	19
CARE HOME STAFF								
Staff mix and supporting residents' needs	37	46	32	34	67	42	136	41
Recruitment and retention	41	51	37	39	44	28	122	37
Appreciating staff	17	21	33	35	60	38	110	33
Staff well-being	20	25	14	15	54	34	88	26
Staff relationships	12	15	25	26	25	16	62	19
Leadership	16	20	9	9	19	12	44	13
Staff training and development	7	9	2	2	23	15	32	10
Shift patterns	6	7	5	5	14	9	25	7

* Participants could select more than one area of importance

** Proportion of the total no. respondents within that particular grouping (i.e. residents, relatives or staff)

DISCUSSION

This is the first UK research priority setting study in care homes for older people to jointly gather perspectives of residents, relatives *and* staff. It shows generating and prioritising uncertainties and researchable questions with care home communities is feasible and informative. The 319 uncertainties, six broad, and 38 sub themes reveal the breadth and commonality in researchable questions. The majority (86%) were foreground questions; complex and indicating the need for information generated through research, and 14% were background questions which can be addressed without research. When considering the priorities, there were similarities and differences across groups. The *meaningful activities* sub-theme was prioritised by residents, relatives and staff. *Staff recruitment and retention* and *enjoying living with others* were prioritised by residents and relatives, and having *support with emotions*, and *dignity and respect* were prioritised by relatives and staff. There were also some differences between residents, relatives, and staff priorities; the following subthemes were prioritised by only one participant group: *understand and manage distress*, *understanding care homes*, *access to health and care services*, *healthcare sector understanding care homes*, *having choice*, *falling*, and *staff mix and supporting residents' needs*. As society strives to adjust to greater numbers of older people, with associated care needs, the prioritised subthemes represent uncertainties that matter most to those most affected by research processes and outcomes. Such targets could help research commissioning efforts.

Our findings align with other studies of care home research priorities. Rayner et al. [17] studied research priorities in Australian care homes, and reported, from the perspective of staff, the importance of: staffing levels and mix, attracting, recruiting, and retaining staff, and the need for effective strategies to help support residents with behavioural and psychological symptoms of dementia. In the UK, Shepherd et al. (2017), capturing the research priorities of care home staff, found questions about resident dignity and respect, staff recruitment, activities for residents, and better understanding of staffing levels and mix the most important.

The Rayner et al. and Shepherd et al. studies are more than five years old but the importance of staff mix and levels in our study, suggests this is an enduring uncertainty for care homes. Interestingly, Shepherd et al. (2017) did not prioritise staff *retention*. Our findings, reveal that staff recruitment *and retention* were important for both residents and relatives.

Priorities can have empirical and theoretical bases. Empirically, the current UK social care workforce is experiencing an acute crisis in both recruitment (many posts left unfilled) and retention (the net removal of skilled and experienced workers) [18]. But questions about quality (of experience, care and life) in homes can also be explained theoretically. Haunch et al. [19] in their review of empirical studies of staffing and quality in homes, found staff numbers, skills and behaviours the generative mechanism behind quality. Spilsbury et al. relate this empirically to quality, but as it is *experienced* [20]. Concerns about recruiting sufficient numbers of the right staff and retaining them could conceivably stem from perfectly reasonable expectations that people should be able to receive (and deliver) quality care.

The sub-themes residents and relatives prioritised in our study, that Shepherd et al. [9] did not reveal as priorities, represent new priority areas: residents enjoying living together, healthcare staff understanding residents' needs, accessing health and care services, residents having choice in what they do, support with emotions, and falls). This additional knowledge highlights the value of including residents *and* relatives and staff in research.

Implications for research and practice

A core value of the UK's national funder for applied research in social care [1] is funding research that addresses the needs of service users, carers, communities and the public [21]. The questions

and priorities from our study are an expression of these needs. Research funders may wish to consider combing our findings alongside other sources of expressed need (for example, resource availability, interventional availability and effects, demographic predictions, political choices) to inform research commissioning.

Evidence based policy and practice is a requirement for many professionals and their preparatory programmes. The starting point for evidence-based approaches to improving practice is the axiom that some forms of research evidence are better suited to providing reliable and trustworthy information to reduce certain forms of uncertainty [22]. For example, to resolve interventional uncertainty about “which choice is likely to be more effective?” then hierarchies of comparative research designs can help. Conversely, uncertainties derived from experiential gaps in knowledge are better suited to research designs in which rich qualitative description is the goal [23]. The prioritised questions in our study might usefully act as the basis for increasing the relevance of education and training in evidence-based searching (appraisal and implementation) for social care professionals.

Addressing the range of prioritised topics and questions will require partnership working between care home researchers and residents, relatives and staff. Differing disciplines, expertise, and skillsets will make for better research. But the care sector’s fiscal and workforce difficulties (e.g. rising costs, staff shortages), mean efforts must be supportive, build research and implementation capacity, and be sensitive to the need to not impose further burden on over-burdened care home staff [24].

Researcher and practice communities may wish to examine which of our uncertainties can be addressed by *existing* evidence. In the absence of reliable and trustworthy evidence, research and practice communities could also plan and undertake the studies needed to plug the (information) gap. Research and practice partnerships such as the Living Lab in Ageing and Long-Term Care (Maastricht, The Netherlands [25]) and Nurturing Innovation in Care Homes Excellence in Leeds (NICHE-Leeds, UK [26]) have operationalised the generation of locally relevant uncertainties, reflecting national (and international) priorities, as a basis for their research. Griffiths et al [27], provides an example of how researchers and care home stakeholders worked collaboratively to develop and evaluate evidence-based mouth and oral care interventions based on an initial uncertainty and question from a single staff carer in one home.

Care home uncertainties, questions, and priorities will likely change over time. We suggest our findings are treated as “live” and regularly refreshed and updated. They could be viewed alongside relevant uncertainties gathered through public feedback mechanisms, such as the ‘suggest a research topic’ functions in the UK[28], the ‘research priorities portal’ in Australia [29] and research query function in Canada [30].

Strengths and limitations

Our study included staff often absent from research (for example, night staff). The comprehensive and current dataset of questions were generated from residents, relatives and staff, and participants represented care homes located in Scotland and northern and southern areas of England. The care homes were located in urban, rural and coastal geographical areas. To improve generalisability, future research may consider including, other jurisdictions, the perspectives of policy stakeholders, residents with cognitive limitations, and participants representing ethnic minority groups. This is particularly important given the UK’s current commitment to promote equality, diversity and inclusion in health and care research [31]. Different approaches to and adaptation of our methods (data collection, prioritisation techniques) may be needed to ensure that the perspectives of these groups are appropriately gathered and incorporated. We relied on care home staff and researchers supporting residents to complete the survey; potentially introducing a social-desirability bias to

participant responses. Whilst we took steps to minimise bias (for example, open questions, sufficient time with skilled and experienced researchers) we did not explore the empirical effects of possible biases. Balancing inclusivity with methodological rigour remains a key research challenge.

Conclusion

This study has shown how uncertainty-based research priorities can be gathered from residents, relatives, and staff in care homes. Our findings might be used to form a research and practice improvement agenda. The questions gathered and topics prioritised are wide ranging but often share common ground within and between stakeholder communities and over time. Addressing these will require collaborative and interdisciplinary working between research and practice communities to close the evidence and practice gap (where evidence exists) and knowledge gap (where evidence is poor quality or absent). With the current difficulties in the care sector, it is critical for researcher and funder groups to work with care homes in ways that are supportive in building care home research capacity and readiness for evidence-based improvement.

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