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SEeking AnsweRs for Care Homes during the COVID-19 pandemic (COVID SEARCH)

Short report submitted for consideration in *Age and Ageing*

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KEY POINTS

- The COVID-19 pandemic has created new and unanticipated uncertainties for care home staff caring for older people
- A self-formed closed WhatsApp™ group provided a platform for information sharing and support among care home staff during the pandemic
- Just under one-third of staff uncertainties could be addressed through timely, responsive and unambiguous guidance
- A sector informed research agenda has been established from our analyses
- The experiences of care home staff should serve to focus the evidence-based response to the pandemic in care homes

ABSTRACT

The care and support of older people residing in long-term care facilities during the COVID-19 pandemic has created new and unanticipated uncertainties for staff. In this short report, we present our analyses of the uncertainties of care home managers and staff expressed in a self-formed closed WhatsApp™ discussion group during the first stages of the pandemic in the UK. We categorised their wide-ranging questions to understand what information would address these uncertainties and provide support. We have been able to demonstrate that almost one-third of these uncertainties could have been tackled immediately through timely, responsive and unambiguous fact-based guidance. The other uncertainties require appraisal, synthesis and summary of existing evidence, commissioning or provision of a sector- informed research agenda for the medium- to longer-term. The questions represent wider internationally relevant care home pandemic related uncertainties.

INTRODUCTION

COVID-19 has tragically impacted on long-term care worldwide, particularly for older people living in care homes [1]. Incidence and mortality rates vary internationally, but estimates suggest 19-72% of all COVID-19 deaths have been in care homes [2]. The pandemic, screening, diagnosis, management, and ongoing clinical and workforce challenges have created novel, unanticipated, uncertainties for those caring for older residents. This is a vulnerable population, often living with frailty, multiple long-term conditions and disability [3] and at far greater risk of harm from COVID-19.

This short report presents our analysis of uncertainties raised by care home managers and staff that self-formed a closed WhatsApp™ discussion group to support members during the early pandemic phase in the UK. The uncertainties are contextualised in the UK experience but internationally relevant given the shared experiences of many countries.

AIMS

1. To identify care and organisational questions and uncertainties expressed by care home staff;
2. To understand what information would address these uncertainties and provide support in the short-, medium- and long-term.

METHODS

We used the principles of the NICHE-Leeds university-care sector partnership (<https://niche.leeds.ac.uk/>), replicating the Dutch Living Lab on Ageing and Long-Term Care [4]. The core principle of this approach is interdisciplinary collaboration between scientists and care providers to improve the quality of care, life and work for those living and working in care homes. Embedded 'link' researcher roles were adapted for a social media context. Working as 'virtual link' researchers within the WhatsApp™ group we identified questions and uncertainties raised by the 250 care home staff members and considered how, and if, these uncertainties could be resolved.

We used 4 sequential stages - March to June 2020. First, researchers (KS, RD) exported weekly captures of WhatsApp™ discussion as text from 23 March to 17 May. Each week generated approximately 70 pages of text for screening. Identifiable information was removed and text retained only if it met the inclusion criteria (Box 1); all other text was deleted. We identified "raw" (verbatim) questions asked by WhatsApp™ group members or generated a raw question from the discussion text (KS, RD, AG). These questions (rather than the WhatsApp™ text) are the data presented in this paper. Raw questions were grouped into initial themes (n=20). Next, questions were categorised as background or foreground [5], reflecting their underlying uncertainty. Background questions represent the need for "facts". Awareness of the relevant and correct facts generally resolves underlying uncertainty. Often beginning with "what", "where" or "when", reliable answers generally exist, and are reasonably static. Examples of background questions included, "Do guidelines exist for managing Covid-19 infections in care homes?" or "What support, including financial, is available for care homes to plan for and manage staffing shortages during the pandemic?"

Foreground questions are of a different conceptual and cognitive order of complexity. There is often no immediate “correct” answer. Answering foreground questions involves engaging with knowledge designed to systematically and reliably reduce uncertainty in bias-minimising ways: scientific research.

The initial themes were merged using inductive thematic analysis [6] and discussion between team members into 9 higher-order themes (KS, RD, AG). Raw foreground questions were further refined (CT, KS) and validated with a sample of group members; providing a basis for searching (using the 6s approach [7]) for research information. Lack of consensus on questions generated were resolved through discussion and/or sense-checking with a group member. Finally, drawing on the team’s knowledge and information science and care home expertise, we determined and listed information sources likely to address uncertainties and listed questions constituting a sector-informed research agenda.

This was classed as service evaluation and development rather than research [8]. From the outset, the WhatsApp™ group agreed we could identify questions and uncertainties from the discussions. We adhered to the principles of ethical conduct and the anonymity of all WhatsApp™ group members was maintained.

RESULTS

Questions and uncertainties were wide ranging in the early stages of the UK pandemic; 118 questions and uncertainties fell into 9 main themes (in no order of priority):

1. Supporting residents, relatives and staff (n=12)
2. Maintaining an effective workforce (n=13)
3. Interacting with healthcare services (n=6)
4. Organisational impact (n=5)
5. Maintaining effective care (n=12)
6. Enhancing information sharing and learning (n=4)
7. Valuing the contribution of care homes (n=3)
8. Infection prevention and control (n=49)
9. The virus and the individual: symptoms and treatment (n=14)

There were 34 background raw questions (28% of all questions, see table 1) and 84 foreground questions (Table 2). Over two-thirds of the questions (72%) were of this type. Possible combinations of question focus, problem options and outcomes may appear almost infinite but foreground questions represented finite types of uncertainty: (i) effectiveness (what works/might work?); (ii) diagnostic (what is going on here/causing this?) and (iii) prognostic (what is likely to happen?) [9]. Care home managers and staff consistently and overwhelmingly asked “effectiveness” questions.

Most questions and uncertainties related to infection prevention and control (41.5%; n=49), including uncertainties pertaining to personal protective equipment (PPE), isolation of residents and staff, zoning (or cohorting) of residents and/ or staff in the care home, and testing. More than a third (38%) of infection control and prevention questions were “fact-based” (background) questions; resolvable through efficiently targeting extant materials such as guidelines and fact sheets.

DISCUSSION

We believe this is the first systematic capture of the questions and uncertainties expressed by care home staff in the early stages of the COVID-19 pandemic. Questions and uncertainties were wide ranging but focused on symptoms and treatment, infection prevention and control, maintaining effective care and support for individuals living and working in care homes, promoting working relationships across health and care for resident benefit, and managing organisational impact.

Almost one-third of the questions and uncertainties could have been addressed by clear and efficient signposting of care home staff to guidance. For example, the question, “Do guidelines exist?” is relatively easily resolved, “Yes, guidelines can be found here...”. Our analyses revealed that these basic information needs of care home staff were not satisfied. There are a range of explanations for this; no statutory guidance; conflicting guidance; and staff ignorance of guidance. Scant care home-specific guidance during the early stages of the pandemic has been recognised, as has the proliferation of – sometimes conflicting – guidance during later stages [10]. It is likely that similar questions were raised by staff at different times for different reasons.

Effectiveness questions (or “what works?”) reflected the phase of the pandemic and work as context. UK care homes are a mixed economy [11] and responses to the pandemic varied. The WhatsApp™ group was setup to facilitate information sharing and peer support precisely because of this variation. We argue many UK care homes have been in “responsiveness” mode since February 2020; focusing on “doing” rather than detailed planning. Strategizing and associated diagnosing, forecasting and prognosticating has been a lower priority in this time and human-resource-constrained period. As developing effective strategy becomes more pressing, diagnostic and prognostic uncertainties will likely generate new questions – in particular for managers. Because definitive answers to foreground questions are unlikely, these questions offer a target for researchers wanting to use methods best suited to reliably reducing uncertainties most relevant for care homes. This work should inform future research agendas. The WhatsApp™ group remains active and further analyses will reveal changing information needs. For example, during this period, there was minimal mention of contact tracing in the context of testing; this is likely to emerge as a more important issue as care homes adapt to viral threat as ‘business as usual’.

Nuanced typologies of foreground questions exist for specific contexts, such as nursing [12]. We found three broad categories (effectiveness, diagnosis and prognosis) applied to the application of information for resolving uncertainty in care homes. Despite the uncertainty, care staff must undertake judgements, choices and reasoned-action [13]. Finding ways to support the sector is important. We think useful starting points are: (i) addressing the fact-based questions that can be tackled immediately by policy makers, commissioners and regulators - just under one-third of questions (28%) could be addressed in this way; and (ii) undertaking the appraisal, synthesis, and summary of existing evidence and identifying the need for further research in response to the foreground uncertainties of care staff.

CONCLUSION

Analysing discussion in a self-formed closed WhatsApp™ group for care home staff enabled the capture of questions and uncertainties from an 8-week period at the onset of the COVID-19 pandemic. This is important analyses as it captures the uncertainties faced by, and shared between, care home managers and staff. It also highlights the importance of peer support during the pandemic. Categorising these questions and uncertainties helps staff recognise the information sources required to resolve them and help support the sector during the pandemic (short-term) and for adaptation and recovery in the, post-pandemic, medium to longer-term. The questions here are relevant to those countries in a similar position to the UK in March-May and those experiencing outbreaks. The experiences of care home staff should serve to focus the evidence-based response to the pandemic in care homes.

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Disclaimer

The views and opinions expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care.

Conflicts of interest

There are no known conflicts of interest. Members of the team are care providers (Akrill, Astle, Hodkinson).

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ACCEPTED MANUSCRIPT

Box 1: Inclusion and exclusion criteria for text extraction**Inclusion:**

- text where people ask questions or express uncertainties
- text where people ask for information/guidance/signposting about certain topics
- text where people describe a scenario in the care home related to care or organisation of care

Exclusion:

- text where members provide emotional support, encouragement or express religious/spiritual based support for each other (and therefore considered personal)

Table 1: Fact-based (background) questions

All question should be read with the suffix "...in the context of a pandemic."

Supporting residents, relatives and staff What guidance is available to facilitate conversations about do not attempt resuscitation with residents?
Maintaining an effective care home workforce What are the minimum requirements for care workers/volunteers to start working in care homes? Can DBS applications for new employees be fast tracked during the pandemic? What policies and procedures are in place for COVID-19 testing for new employees? What support, including financial, is available for care homes to plan for and manage staffing shortages during the pandemic? What are the insurance implications for care staff delivering nursing tasks during the pandemic? What are the eligibility criteria for the Government's furlough scheme? How is mutual aid (NHS nurse working in care homes) being implemented in practice?
Interacting with healthcare -
Organisational impact Is there financial support available from the government to help cover the additional expenditure (e.g. extra staffing, purchasing PPE) and loss of care home income during the pandemic? Will future care home insurance policies be affected in care homes affected by COVID-19? Does care home insurance cover the costs associated with admitting new residents from hospital diagnosed with COVID-19?
Maintaining effective care How should care home staff complete and document COVID-19 related risk assessments and care plans? Who is authorised to complete Do Not Attempt Resuscitation (DNAR), Recommended Summary Plan for Emergency Care and Treatment (ReSPECT), and similar forms during the COVID-19 pandemic? Whose responsibility is it to report care home deaths related to COVID-19?
Enhancing information sharing and learning Where can care homes find appropriate and up-to-date regional and national guidance?
Valuing the contribution of care homes -
Infection prevention and control Who are the recommended suppliers of PPE for care homes?

How will care home providers be reimbursed for the extra financial costs they incur during the pandemic?

What guidance exists for self-isolation of residents returning from hospital?

Is there guidance around how care homes can use tracking and tracing for residents with COVID-19?

What is the guidance around self-isolating when living with someone who has COVID19 symptoms?

If a care worker has been exposed to COVID19 should they self-isolate?

Do all staff (including those on zero hour contracts) get paid whilst self-isolating?

What are the criteria for care workers to shield themselves and be eligible for furlough leave?

Are those living with vulnerable household members, those with underlying health issues, or those over the age of 70 included in the furlough scheme?

What guidance and process should care home employers follow when furloughing staff?

What date does the self-isolation period start, from the date the symptoms started, the date the test was taken, or the date of receiving the positive COVID result?

If staff have mild symptoms after self-isolating from COVID19, can he/she return to work?

The 111 service gave care staff wrong advice regarding length of self-isolation, how can the care manager complain about this?

How do care home staff access testing for COVID-19?

What arrangements are in place to ensure accessibility of testing for care home staff?

How do care home residents' access testing for COVID-19?

Which members of staff can conduct COVID-19 testing in care homes and what guidance and/or training is provided for care home staff to undertake this role?

What is the timeframe in care homes for receiving results following a test, and what is an optimal timeframe?

The virus and the individual: symptoms and treatment

-

Table 2: Research-based (foreground) questions

All question should be read with the suffix "...in the context of a pandemic."

Supporting residents, relatives and staff

What are optimum strategies for increasing sense of comfort in residents?
Which activities offer minimal risk of staff-resident or resident-resident COVID-19 infection?
How effective are staff strategies for minimising safety-focused anxiety in relatives of residents?
Which strategies most effectively increase compliance with self-isolation requirements in relatives and residents?
Which strategies most effectively promote relative-resident continuing communication?
Which strategies for managing visits to a home lead to the least adverse safety events?
What are the most effective methods of improving feelings of emotional and practical support in care home staff?
How effective are methods of support delivered outside the workplace for care home staff?
What interventions promote feelings of staff safety in care homes?
Which in-home communication strategies lead to most understanding and positive behaviours related to COVID-19 in care home staff?
Which methods of staff feedback on COVID-19 management in homes lead to highest levels of satisfaction with processes?

Maintaining an effective care home workforce

Which organisational interventions are most effective in increasing feelings of support and readiness in new care workers?
What is the impact on diagnostic performance of training for COVID-19 symptom recognition in care home staff?
What is the impact on time-to-adoption of methods for encouraging uptake of new roles in care staff?
What strategies are effective for ensuring consistency in training and information for care home staff?
Which recruitment strategies most effectively lead to higher skilled entrants to care home workforce?
What is the impact on quality of care of volunteer roles in homes?

Interacting with healthcare

Which methods for structured transition between hospitals and homes lead to highest quality communication (maximum transfer of information/least loss of information)?
Which assessment information is viewed as essential by care home staff receiving residents from hospital?
Which methods of sharing care plans with healthcare professionals lead to the least loss of information/continuity of preference sensitive care?
Which strategies lead to the highest levels of perceived collaborative working between health systems and care homes?
Which interventions are most effective in maintaining appropriate prescribing for residents?

Which methods of communicating information-related concerns between homes and the NHS lead to increased information flow and satisfaction among staff?

Organisational impact

What strategies are effective in helping homes respond to the financial challenges associated with COVID-19?

Which strategies most effectively maintain continuity in supplies to care homes?

Maintaining effective care

What admission procedures promote feelings of safety and comfort for new residents with minimal information?

What is the impact on mortality and morbidity of a policy of accepting new residents i) suspected of and/or ii) confirmed as being COVID-19 positive?

What strategies most effectively reduce the risk of infection from residents arriving from hospital or home?

What strategies most effectively increase the proportion of residents and relatives with advance care plans?

Which strategies for end of life care lead to highest reported quality of death/perceived levels of support from relatives in care homes?

Which interventions for use in end of life visiting are most effective in preventing transmission of COVID-19?

Which interventions to encourage the acquisition of competencies in verifying death lead most effectively to enhanced feelings of support?

Which approaches to advanced care planning lead to highest levels of perceived support/satisfaction with the process?

What is the impact on resident and home related adverse events of reusing end of life medicines?

Enhancing information sharing and learning

Which methods for communicating content (guidelines, resources) related to COVID-19 lead to highest levels of understanding and positive behaviours in homes?

Which lessons from the 1st wave of the pandemic are perceived as the most important for preparing for future pandemic spikes/waves by care home staff?

Which tools most effectively lead to perceived quality of relationship building and communication between providers and commissioners in health and social care systems?

Valuing the contribution of care homes

Which strategies most effectively increase perceived value of care sector amongst policy makers?

What is the impact on involvement numbers and perceived quality of interventions to increase staff input into policy decision making?

Which managerial strategies most effectively reduce the number of home related news stories containing harmful misinformation?

Infection prevention and control

What is the impact on infection transmission rates of differing PPE regimes for common processes in care homes?

What is the impact on infection transmission rates of differing PPE timing and frequency regimes in care homes?

Which methods for disposal of PPE most effectively reduce COVID-19 infection transmission?

Which stock control strategies most effectively maintain continuity of supply of PPE?

What are the optimal procurement strategies for PPE at minimum cost?

Which combination of PPE equipment most effectively reduces infection transmission risk in homes?

Which barrier nursing regimes most effectively reduce COVID-19 infection transmission rates?

Which managerial strategies most effectively increase confidence in PPE use amongst staff?

What are effective strategies for minimising panic attacks or other symptoms in staff with heightened anxiety regarding PPE usage?

What is the impact of hypoallergenic alternative PPE for staff with allergies to common PPE materials?

Which symptoms most accurately predict the need for self-isolation?

What is the impact on transmission rates and mortality of single resident vs. whole home isolation?

Which interventions/strategies are most effective in helping people living with dementia or other forms of impaired cognition to self-isolate?

Which strategies for minimising transmission risks during meals in homes most effectively reduce infection rates?

What is the impact of interventions designed to maintain/improve physical and mental health in residents?

What is the impact on perceived support in residents of interventions to minimise the effects of visiting restrictions in homes?

What is the effect on adverse events in residents self-isolating?

Is self-isolating an acceptable intervention for residents?

Which implementation (of zoning) strategies most effectively reduce COVID-19 transmission rates in homes?

How have care home staff and residents experienced zoning implementation?

Are higher levels of compliance with self-isolating behaviours in staff suspected of being exposed to COVID-19 associated with lower transmission rates in homes?

What is the optimal time for self-isolating for staff with COVID-19 symptoms to minimise infection transmission in homes?

What is the impact on transmission rates in homes where staff that have recovered from confirmed COVID-19 self-isolate again when a household member develops symptoms?

What is the effect on transmission rates of whole home asymptomatic testing of residents?

What is the level of burden experienced by managers implementing and responding to testing in homes?

How accurate are antigen and antibody tests for COVID-19 in care homes?

What is the positive and negative predictive value (or area under the ROC curve) of antigen and antibody tests for COVID-19 in care homes?

What has been the impact on staff and resident transmission rates and experiences of mass testing in homes in other countries?

Does collecting additional clinical information from residents whilst waiting for test results lead to reduced transmission rates and mortality in homes?

The virus and the individual: symptoms and treatment

Which symptoms distinguish COVID-19 from chest infection due to other causes in care home residents?

Which monitoring strategies for residents suspected of having COVID-19 result in lowest transmission rates and mortality?

Are there patterns in the trajectory of COVID-19 virus in older people?
How effective is paracetamol for reducing symptom of a high temperature in older people with suspected COVID-19?
How should staff effectively support residents to maintain their hydration when infected?
Are sub-cutaneous fluids effective for managing symptoms of COVID-19 in older people? How can subcutaneous fluids be safely administered in care homes?
Is oxygen therapy effective for managing symptoms of COVID-19 in older people?
Are antibiotics effective for treating symptoms of COVID-19 in older people?
Should an older person with a diagnosis of COVID-19 continue taking their usual medicines?
How can staff best promote and advocate for residents to ensure timely and appropriate treatment and care during the pandemic?
What are the benefits of using a frailty score rather than a comorbidity score (such as the Charlson index) for triage into critical care?
Once a resident has recovered from COVID-19, what risk do they present for infection transmission to other residents and staff?
How effective are air cleaning machines for reducing the spread of COVID-19 in care homes?
Can thermometer covers be cleaned and re-used?