

Bridging the Gap Between Infection Prevention Guidance and Dementia Care: A Qualitative Study of Healthcare Professionals' and Family Caregivers' Experiences

Bethany Linder

University of Brighton and University of Sussex

Jackie A. Cassell

University of Brighton and University of Sussex

Eddy J. Davelaar

University of London

Dorina Cadar

d.cadar@bsms.ac.uk

University of Brighton and University of Sussex

Research Article

Keywords: dementia, family caregivers, infection prevention and control, qualitative research, care homes, health communication, person-centred care

Posted Date: October 20th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-11414923/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Additional Declarations: No competing interests reported.

Abstract

Background

Infection prevention guidance is essential to the safety of older people receiving care, but its implementation may be difficult when recommendations do not account for the cognitive, behavioural and sensory needs of people living with dementia. We explored how healthcare professionals and family caregivers received, communicated and adapted infection-related guidance during the COVID-19 pandemic, and what their experiences suggest for future dementia care.

Methods

We conducted semi-structured interviews via Microsoft Teams with 10 healthcare professionals and 10 family caregivers in the UK between August 2024 and February 2025. Interviews explored experiences of accessing, interpreting and communicating infection-related guidance. Data were examined using reflexive thematic analysis.

Results

Three themes described receiving, sharing and adapting guidance. Participants reported frequent changes, delayed or unclear messages and limited dementia-specific advice. Isolation, visiting restrictions and mask wearing were described as difficult to implement when they conflicted with cognitive needs, established routines or emotional wellbeing. Professionals and caregivers often interpreted and adapted generic guidance themselves. Participants valued trusted and timely information, individually tailored explanations, concise language, visual and audio materials, and accessible repositories of verified resources.

Conclusions

Participants' accounts reveal a gap between general infection prevention recommendations and their practical use in dementia care. Guidance designed with people affected by dementia, caregivers, and frontline professionals, and offered in accessible formats with proportionate implementation options, may support more feasible, person-centred responses to future outbreaks. The effectiveness of such approaches requires evaluation.

Background

People living with dementia may face particular challenges when infection prevention measures require them to understand, remember and act on unfamiliar instructions. Cognitive impairment, behavioural changes, and sensory difficulties can affect how information is communicated and how precautions are

implemented in everyday care [1, 2, 3]. These challenges are especially relevant in care homes and other settings where close contact, personal care and shared spaces are integral to daily life [4]. Infection prevention guidance therefore needs to be considered not only as a statement of recommended practice, but also as information that people with dementia, family caregivers and care staff must be able to use.

A central challenge for dementia care is the potential mismatch between general infection prevention recommendations and the circumstances in which care is provided. Measures that seem straightforward in public guidance, such as isolation, distancing, or wearing face coverings, may be hard to explain or apply to someone who needs frequent reassurance, close personal support, or familiar routines. When guidance does not explain how to respond in these circumstances, family caregivers and frontline professionals may bear responsibility for interpretation. This raises questions about feasibility, consistency and the balance between infection risk and person-centred wellbeing.

The COVID-19 pandemic brought these tensions into sharp focus. People living with dementia experienced increased risks of adverse COVID-19 outcomes, while families and care services faced changing restrictions and substantial disruption [5, 6, 7, 8]. Research has documented the pressures care workers faced and the difficulties of applying rapidly changing guidance [9, 10]. Yet understanding how guidance moved from national communication to individual care decisions remains important for improving preparedness for future infectious outbreaks.

The issue extends beyond the accessibility of written materials. Usable guidance must reach people promptly, provide clear, trustworthy information, and adapt to different cognitive abilities, communication preferences, and care environments. The need to protect against infection may also conflict with maintaining relationships, autonomy and emotional wellbeing. These competing considerations make both family caregivers' and professionals' experiences important sources of insight into how recommendations are interpreted in practice.

Previous work has highlighted communication needs in dementia and the effects of pandemic restrictions [3, 11, 12]. Our study focuses specifically on the pathway from receiving infection-related guidance to communicating and adapting it in dementia care. By examining this process from professional and family perspectives, we sought to identify where participants found generic guidance insufficient and which practical supports, they found useful.

We therefore explored retrospective accounts of COVID-19 and other infection-related guidance among healthcare professionals and family caregivers in the UK. The study aimed to understand the challenges of applying recommendations in the context of dementia and to identify considerations for more accessible, feasible and person-centred infection prevention communication in care homes and community settings.

Research objectives:

1. Explore the experiences of healthcare professionals and family caregivers in receiving, interpreting, and communicating COVID-19 and other infection-related health guidance to people living with dementia.
2. Identify practical requirements and implementation supports that enable effective communication of health guidance to people living with dementia.
3. Identify adaptations to the content and delivery of guidance that make infection-related advice usable for people living with dementia, taking account of cognitive, behavioural, and sensory challenges.

Methods

Study Design

This study used a qualitative, interpretivist approach, using semi-structured interviews to explore how healthcare professionals and family caregivers communicated infection-related health guidance, particularly during the COVID-19 pandemic, to people living with dementia. The study focused on the implementation pathway from receiving guidance to translating, communicating, and adapting it in everyday practice across community and care settings.

Participants and Recruitment

Participants were recruited from three sources: Join Dementia Research (JDR), Prolific and social media advertisements. Participants were required to be over 18 and to have lived in the UK since at least January 2019. Family caregivers were required to be a caregiver of someone who was diagnosed with dementia prior to January 2019 to ensure that participants had experience with dementia prior to and during the COVID-19 pandemic. Healthcare professionals were required to be involved with infection control as part of their role and to have some contact with people living with dementia or their caregivers. These eligibility criteria were used to ensure participants could reflect on how guidance was accessed and applied during periods of rapid change in UK infection control messaging.

Participants were contacted by the first author by email. Participants were given a participant information leaflet about the study and asked about their availability to take part in an interview. The study used a convenience sample; data from those invited to participate but who did not respond were not collected. After completing an interview, participants received £20 as compensation for their time. Recruitment continued until the research team judged that the dataset provided sufficient 'information power' to address the study aims, given the specificity of the sample and the depth of interviews.

All interviews and transcriptions were carried out by the first author, a female researcher with a PhD in Health Sciences, a master's degree in social science research, and experience and training in conducting individual and group qualitative interviews. No interviewee had met the interviewer prior to being contacted to take part in the study, and no additional people were present during the individual

interviews or the focus group. Interviewees were informed that the United Kingdom Health Security Agency (UKHSA) funded the study and that the project aimed to determine whether health guidance could be adapted to better meet the needs of people affected by dementia. No repeat interviews were carried out, and all interviews took place between August 2024 and February 2025. The interviewer adopted a reflexive stance, consistently using the topic guide while allowing participants to describe how they interpreted the guidance, the practical constraints they faced, and the strategies they used to support understanding and adherence.

Data Collection

Interviews followed semi-structured interview guides that differed for healthcare professionals and family caregivers (see supplementary material, Tables S1 & S2). The interview guide for family caregivers was developed with assistance from a Patient and Public Involvement (PPI) group comprising nine people living with dementia and their caregivers, and the interview guide for healthcare professionals was developed with assistance from a public health professional. The guides were designed to elicit how infection-related guidance was accessed, interpreted, communicated, and adapted in practice, and what supported or hindered implementation in dementia care contexts.

Healthcare professionals were asked about their experiences in receiving and implementing infection control guidance, communicating it to people with dementia and others with communication difficulties, and communicating it to other healthcare workers. We asked family caregivers about their experiences during the pandemic and their views on the suitability of COVID-19 guidance for people living with dementia and their families, including how they translated generic guidance into everyday routines and managed distress or resistance.

All interviews were conducted online using Microsoft Teams. All healthcare professionals participated in individual interviews, and family caregivers could choose an individual interview or a focus group, based on their preferences and availability. Individual interviews lasted 40–60 minutes, and the focus group lasted about 1.5 hours. Before interviews began, healthcare professionals gave verbal informed consent, and family caregivers provided written consent. Interviews were audio- and video-recorded and were transcribed verbatim. We anonymised any identifiable information in the transcripts and assigned participants a participant number to protect their identities. Healthcare workers were assigned an 'H' before their number (e.g., Participant H1), and family caregivers were assigned a 'C' before their number (e.g., Participant C11). Participants were encouraged to provide concrete examples of guidance materials (e.g., leaflets, webpages, local policies) and to describe the practical steps involved in communicating and applying them.

This study followed the COnsolidated criteria for REporting Qualitative research (COREQ) checklist to ensure comprehensive reporting of qualitative methods and findings (Tong et al., 2007; see Supplementary Table S3).

Data Analysis

An interpretivist theoretical approach underpins the present study. We used reflexive thematic analysis to derive themes from the data, following the six stages of reflexive thematic analysis outlined by [21]. The analysis was oriented to understanding the implementation pathway of infection-related guidance in dementia contexts, including how guidance was received, interpreted, communicated, and adapted in everyday care. The first author primarily conducted the analysis, with iterative input from the co-authors through discussion and theme refinement.

First, the researcher read the transcripts multiple times for familiarisation. At this stage, the researcher listened to the recordings again and made preliminary notes about potential patterns within the data. The researcher used NVivo 12 to aid in coding the transcripts. The researcher used an iterative coding approach, revisiting previous transcripts as new concepts emerged and allowing the researcher's understanding of the data to evolve. Coding attended to both barriers and facilitators to communication and implementation (for example, characteristics of guidance materials, routes of dissemination, trust and timeliness, and practical feasibility within care routines).

After coding, the initial themes were constructed by identifying related codes that had shared meaning. These initial themes were then refined through critical discussions with co-authors to ensure that themes captured the practical processes and constraints described by participants across settings and roles. Data saturation was not discussed because it is not compatible with reflexive thematic analysis [14]. Themes and sub-themes were then named and organised. The researcher drew on relevant literature throughout the analysis to inform their interpretation of the findings and to consider how the present work relates to the broader literature. Throughout the analysis, the researcher collected notes in a reflexivity diary. No member checking of transcripts or findings took place. Given the study's aims and analytic approach, credibility was supported by a transparent description of recruitment, data collection, and analytic procedures, along with reflexive documentation and team-based discussion of theme development.

Ethics

This study received ethics approval from the Birkbeck, University of London Ethics Committee (Reference: 2324025). All participants provided informed consent prior to participation (verbal consent for healthcare professionals and written consent for family caregivers). Participants also consented to the anonymous publication of verbatim quotations, and all identifying details were removed during transcription and anonymisation.

Results

Participant Characteristics

A total of 20 participants took part in the interviews, consisting of 10 healthcare professionals (7 female, 3 male) and 10 family caregivers (8 female, 2 male). Of these, 11 participants were recruited via Prolific, 6 via social media advertisements, and 3 via Join Dementia Research. Participants contributed perspectives across both community and care settings, reflecting the cross-sector context in which infection guidance was implemented during the pandemic.

The healthcare professional participants represented a range of professional backgrounds. Five participants (H1-H5) were based in care home settings, two participants (H6-H7) worked in health protection, two participants (H8-H9) were social workers, and one participant (H10) was a nurse (see supplementary Table S4 for a summary of participants' professions). This mix enabled comparison across roles with different responsibilities for receiving, interpreting, and communicating infection guidance.

Demographic data were not collected to protect healthcare professionals' identities, as their job titles are already included. Given the small number of participants within some roles, further demographic details could have increased the risk of deductive disclosure. Demographic data for the family caregivers are reported in Table 1

Table 1
Participant Demographic Data

Demographic	<i>n</i>	%
Age		
40–49	3	30%
50–59	5	50%
60–69	1	10%
70–79	1	10%
Gender		
Female	8	80%
Male	2	20%
Country of Residence		
England	8	80%
Scotland	1	10%
Wales	1	10%
Carer Ethnicity		
White British	7	70%
Asian/Asian British	2	20%
Other ethnicity	1	10%
Dementia Diagnosis of Care Recipient		
Alzheimer's disease	2	20%
Vascular dementia	4	40%
Mixed dementia	2	20%
Other types of dementia	1	10%
Not sure	1	10%
Relationship to Care Recipient		
Spouse/partner	2	20%
Parent/parent-in-law	6	60%
Uncle/aunt	1	10%
Prefer not to say	1	10%

Demographic	<i>n</i>	%
Duration of caring (years)		
	Mean	Range
	6	3–12

Interview findings

A summary of the three themes and their subthemes is presented in Table 2. Participants included healthcare professionals and family caregivers; however, the theme profiles did not differ significantly between the two groups overall. Specific examples will be given where experiences diverge between groups.

Table 2
Summary of the study's themes and sub-themes

Theme	Subthemes
(1) Receiving Guidance	• Trust and timeliness • Lack of dementia-specific guidance • Length and complexity
(2) Giving Guidance	• Communication skills • One-size doesn't fit all • Risk vs. wellbeing
(3) Adapting Guidance	• Adapting the format • Resource library • Signposting to further support • Inclusion

Theme One: Receiving Guidance

Participants described how they accessed and used infection prevention guidance as a practical tool during the COVID-19 pandemic and during outbreaks in care homes and local communities. Overall, they reported that guidance was only usable when it was (1) trusted, (2) timely, and (3) clearly relevant to the setting and to people living with dementia. During the pandemic, some family caregivers and healthcare professionals described COVID-19 guidance as delayed, frequently changing, and insufficiently tailored to dementia care, so it failed to consistently meet these requirements. When guidance was unclear or not fit for purpose, participants reported increased uncertainty and added workload, as carers and staff had to translate generic advice into workable day-to-day practice. Participants felt that limited access to

appropriate, dementia relevant guidance constrained the care and support they could provide during this period.

Trust and timeliness

Most participants considered the National Health Service (NHS) website, government websites, and the mainstream media as trustworthy sources for guidance on COVID-19 and other infections. However, some participants distrusted government and media sources, particularly during the COVID-19 pandemic, which motivated them to seek information elsewhere. This behaviour was particularly pronounced among those who perceived the government's COVID-19 guidance as insufficiently detailed or timely. In these accounts, reduced trust and delays shaped how guidance was implemented in practice, increasing uncertainty and requiring caregivers and staff to fill gaps by searching for additional sources.

"The media would just make up what they [wanted]. A lot of it was Chinese whispers, hearsay, and I wanted hard facts [...] I used social media to try and ask questions that I didn't feel were being answered really in the briefings." (Participant C19, Family Caregiver, Individual Interview)

Some participants highlighted that health guidance translated into different languages can be particularly slow to be released, leaving people more susceptible to misinformation and leading to infections spreading within specific communities. Participants described delays in accessing translated resources as reducing the usefulness of guidance during fast-moving outbreaks and increasing reliance on informal information channels.

"There's a time lag... it can take such a long time to get hold of the [translated] resources to share the information; by then, whatever infection you've had has gone through a care home, has gone through a community." (Participant H6, Public Health Manager)

"If it's not being communicated [in their language yet] ... they're getting their messages from elsewhere, which aren't reliable." (Participant C17, Family Caregiver, Individual Interview)

Lack of dementia-specific guidance

Another difficulty healthcare professionals and family caregivers faced was the lack of relevant, practical guidance for dementia care. Participants described relying on generic public guidance that did not reflect the realities of caring for someone who could not be left alone, could not understand restrictions, or required close physical support.

"[The COVID-19 guidance] really didn't work for [carers]... we just had to do stuff for her and... if anybody didn't like it, then it's like, well, tough, because we can't just leave her. You've just got to do it." (Participant C15, Family Caregiver, Focus Group)

Healthcare professionals similarly reported that they often received no additional dementia specific guidance beyond what was available to the public, leaving them to rely on informal judgment and local

workarounds.

"[I only had access to] the [same] guidance that was given to the public. There was, from memory, nothing that we got that was written that we had to do and say to people [with cognitive impairments]. We just used our own common sense, really. Which was crazy, I suppose." (Participant H8, Social Worker)

Participants who worked in care homes reported that standard infection control guidelines were "impossible" (H3) to implement, and that they would have valued guidance that acknowledged feasibility constraints and provided practical options for managing infection control procedures, notably isolation, when working with residents with dementia.

"It wasn't dementia friendly, the guidance, at all... in a unit where we have people living with advanced dementia who do not understand, are unable to understand infection control procedures that they need to stay in that room. What should you do to minimise the risk of spreading coronavirus? Guidance about that could have been helpful." (Participant H5, Care Home Director)

Length and Complexity

Participants shared their views on how the format of health guidance could be adapted to better meet the needs of the public and healthcare professionals. Across accounts, participants described length and complexity as practical barriers to implementation, particularly when guidance changed rapidly and needed to be communicated in time-pressured settings.

For professionals

Healthcare professionals noted that infection control guidance intended for them can be very lengthy, making it difficult to read during shifts. This was particularly salient during COVID-19, when guidance was updated regularly, making it difficult for healthcare professionals to keep up to date. Participants described this as contributing to confusion and inconsistent uptake across staff teams.

"Every single week it was changing, and it was getting very confusing, really. For all of the staff, it was very confusing." (Participant H1, Senior Carer)

Participants spoke about needing to "interpret" (H3) and "translate" (H6) guidance before sharing it with their colleagues. This was because it was too long for all colleagues to read in a reasonable time, and because some language and concepts were too complex for some to understand. In practice, this meant that implementation relied on local summarising and re-messaging, with potential for variability in what was emphasised and how quickly it reached frontline staff.

For the general public

Some participants believed that health guidance aimed at the general public can also be too complex, and more care should be taken to ensure health information is easy to understand. Participants emphasised that jargon and acronyms limited accessibility, particularly for families trying to apply guidance while supporting someone with cognitive impairment.

"Another thing is they use a lot of acronyms [in health guidance], they use a lot of jargon... simple instructions, that's what people need. They don't need pages of jargon." (Participant C19, Family Caregiver, Individual Interview)

However, one participant noted that striking the right balance between simplicity and enough detail to ensure people understand what they need to know could be difficult. This tension was framed as an implementation challenge: guidance needed to be brief enough to use while still providing sufficient detail for safe decision-making.

"We need a better understanding of how much information is actually needed by people. Because if it's too long, it's not good enough. Like, they're going to get bored. If it's too short, people are in danger, because they don't have enough information to keep them safe." (Participant H6, Public Health Manager)

Theme Two: Sharing Guidance

Participants discussed their experiences with sharing health guidance with people living with dementia in healthcare and community settings. Both healthcare professionals and family caregivers highlighted the need to develop communication skills in order to effectively communicate with people living with dementia, as well as the importance of treating each person with dementia as an individual. However, participants reported challenges with communicating COVID-19 guidance to people with dementia, especially for those with advanced dementia. This theme reports the barriers and facilitators around successfully communicating guidance to people living with dementia.

Communication skills

Participants described the need to develop communication skills for interacting with people with dementia. Communication techniques that facilitated effective communication included accessing training and advice, developing patience, being mindful of individual impairments, and treating people with dementia with respect.

Participants spoke about the need for repetition when communicating about health guidance with people living with dementia, which could be frustrating for caregivers and health professionals. They emphasised that patience helps reduce distress and foster understanding.

"Talk to them in very, very simple language. You sometimes have to repeat yourself as well and just be patient." (Participant C20, Family Caregiver, Individual Interview)

Healthcare professionals discussed the importance of training in communication techniques and the opportunity to receive guidance from more experienced colleagues. Family caregivers valued support from professionals and dementia organisations around communication skills.

"I think it's just regular ongoing training. It's something that you've got to keep up with... and utilising the disability champion." (Participant H10, Nurse)

"Some presentations and talks that people [from charities] have given... about how to even talk to [people living with dementia]... through those I've gained a lot of knowledge." (Participant C20, Family Caregiver, Individual Interview)

Some participants spoke about the importance of treating people living with dementia respectfully by not automatically assuming they are incapable of understanding something. They discussed the importance of giving people the "best chance" (H9) to understand health guidance by explaining it in multiple ways.

"It's all about... talking to them sensibly, you know, sometimes people I think seem to feel that someone's got dementia, and they haven't got a great memory, they equally lack in intellect. So, people sometimes treat them like they're children. So, it's about respecting them as an individual and explaining something." (Participant H4, Care Home Manager)

If at that point the person living with dementia still doesn't understand the health guidance, decisions will ultimately need to be made on their behalf based on their best interests.

"[It's important] not to just assume that everyone with dementia can't understand, but likewise that you shouldn't bother to try. But recognising that it's not always going to be successful, so you do need certain skills to negotiate that issue... in the best possible way," (Participant H3, Care Home Manager)

Being mindful of impairments

As people living with dementia have cognitive impairments, it is important to understand how to communicate in a way that is mindful of this. Participants described how they had to learn to shorten and simplify information to help the people they care for understand health guidance. Some participants discussed how creating written reminders can enhance communication and understanding for individuals living with dementia who experience memory impairments.

"I find with people with dementia, it's having something in hard copy format that they can keep going back to... because obviously they read it, they potentially understand it in that moment. But if you ask them half an hour later, [they've forgotten]." (Participant H9, Social Worker)

Hearing and visual impairments are also common in this population, which, along with cognitive impairments, can exacerbate communication difficulties. Being mindful of these impairments by using communication techniques or adjusting the format of health guidance, for example, providing information in large fonts or an audio version, can help information be communicated effectively.

One size doesn't fit all

Participants emphasised that everyone living with dementia is an individual and will differ in their ability to understand health guidance and the communication strategies that will be most useful when interacting with them. As a result, participants described communication as an iterative process, shaped by the person's symptoms, preferences, and context.

"There's no one [size] fits all with dementia. It affects people in so many different ways that you definitely have to spend time with that person, really, to work out which bit of information is going to be best for them." (Participant H9, Social Worker)

Therefore, it may not be possible to create a single piece of guidance on communicating health information to people affected by dementia, as it may not be applicable to everyone. Instead, it is essential to consider the individual and tailor advice to help them understand. Participants suggested that guidance is most useful when it offers flexible principles and practical options, rather than a single fixed script.

"I don't know if we need the guidance on feeding back information to [people living with dementia] because I think everyone is such an individual, they're never going to be able to write that because what they're saying for one person might be different for someone else." (Participant H1, Senior Carer)

For professionals, having the opportunity to get to know a patient and build rapport helps them communicate about health guidance more effectively. Furthermore, obtaining communication advice from the patient's family members or other professionals who have had more contact with them is valued, where possible. This was described as supporting more consistent communication across staff and settings.

"Speaking [to their family] beforehand about how best to communicate. Is there anything that could make them more comfortable? Is there anything that I could say or do that's going to do that's actually going to frighten them?" (Participant H10, Nurse)

Risk vs. Wellbeing

Participants reported that during the COVID-19 pandemic, people living with dementia often became distressed due to social isolation, disruption to their routines, and difficulty understanding what COVID-19 was and why the guidance was in place. Participants framed this as a practical tension in implementing restrictions while maintaining person-centred care.

"He was a very sociable person and was not able to go out and mix with people, which was, I think, affecting him mentally. He lost a lot of his freedom... he must have felt very depressed." (Participant C18, Family Caregiver, Individual Interview)

Many participants spoke about the difficulties they experienced when sharing COVID-19 guidance with people living with dementia, as even after exhausting many different communication techniques to try to explain it, some were just not able to understand. As a result, participants had to make judgements about how best to keep the people they cared for safe and well, as they lacked the capacity to manage their own safety. However, strictly enforcing COVID-19 restrictions was distressing for people with dementia who did not have the capacity to understand why the limits were being imposed. For example,

one participant spoke about how her mother, who was in a care home, could not understand why her family were not visiting her.

"When we started having telephone calls with mum, all we would get from her was that we'd abandoned her in this place. We didn't love her anymore... I don't think we as a family... will ever come to terms with that. I think it's left a mental health scar on all of us." (Participant C19, Family Caregiver, Individual Interview)

In some circumstances, participants described allowing the people they cared for to engage in behaviours that risked exposing them to COVID-19, as stopping them would be too detrimental to their wellbeing. These accounts illustrate how carers sometimes prioritised immediate wellbeing over strict adherence when guidance felt unworkable.

"At the end of the day, he was his own person, and I could not stop him if he wanted to go out in the middle of the night... there was no, there was no telling him." (Participant C14, Family Caregiver, Focus Group)

Participants spoke about the need for flexibility in health guidance when it comes to people living with dementia, as it is not always possible to follow guidance without causing substantial distress in this population. They emphasised that dementia-inclusive guidance should support proportionate decision-making and acknowledge the need to balance infection risk with psychosocial harm to practice person-centred care.

"Communication was hell; it was very, very difficult. So, the residents asked [if we could remove masks]. We conducted a survey with the residents, staff members, and relatives. The majority of people preferred to remove masks, so that's what we did." (Participant H5, Care Home Director)

"With people with dementia, especially in a care home setting, [there] is always a negotiation of what, you know, what harm and risks are there and what benefits are there ... it's not proportional or reasonable to enforce [a] guideline if it's going to cause undue distress or harm." (Participant H3, Care Home Manager)

Theme Three: Adapting Guidance

Participants expressed frustration with the lack of information adapted into a format suitable for people living with dementia. This theme centres on participants' views of how health guidance could be adapted to better meet this population's needs. Participants described a gap between generic materials and what was usable in dementia care, which often required carers and staff to create local workarounds.

Participants described how materials designed for the general population failed to consider the behavioural, sensory, and physical realities of dementia care. Access to an adapted format is beneficial because it makes it more likely that someone living with dementia can read and understand the guidance independently. It can also help healthcare professionals and family caregivers explain health information to individuals living with dementia, as they can review the materials together. Participants emphasised that adapted formats supported communication in practice and reduced reliance on ad hoc translation by carers and frontline staff.

Adapting the format

Participants discussed a range of practical ways to make health guidance more accessible and meaningful for people with dementia, including:

1. Ensuring the text is concise and uses simple language. Acronyms and *"big medical words"* (H8) should be avoided as much as possible.

"Nobody's going to sit and read a four-page document, but they will read something that's a page long, large font, easy to understand, and just tells me exactly what they need to know." (Participant H4, Care Home Manager)

2. Using images to help convey concepts and make them more visually appealing. Pictures may also be easier to understand for those who have difficulty reading.

"I think the pictures kind of are just easier to understand for people. And I think it grabs their attention a little bit more as well." (Participant H1, Senior Carer)

3. Making videos can be helpful for individuals with difficulty reading, as they may be more engaging than written materials, and can be revisited by those with memory impairments.

"Make it a video [so they can watch repeatedly] ... I can't stay all the time to keep repeating things." (Participant H8, Social Worker)

However, caution is needed when adapting health guidance to ensure that, while materials are simple and easy to understand, they are not perceived as childish or patronising.

"There's a lot of easy-read information out there, and it tends to be a bit too simplistic and a bit old-fashioned. It's all line drawings that have been done, you know, 30 years ago... it's very childish, and we don't have to treat them like that." (Participant H8, Social Worker)

Resource library

Participants reported difficulty locating health materials that had already been adapted for people with dementia. As one public health registrar remarked,

"Unless these things are very clearly signposted and advertised, it can be quite challenging to pick them up." (Participant H7, Public Health Registrar)

This often resulted in participants either lacking the necessary resources, creating their own, or relying on online materials of uncertain legitimacy. Having access to a library of resources adapted for people living with dementia, vetted and approved by trusted health authorities, would save healthcare workers time and support more consistent delivery across settings.

"If there were a bank of information forms in different formats that was available somewhere on some platform, that would be fantastic [...] rather than us having to try and make something because it takes a lot of time." (Participant H4, Care Home Manager)

Participants also highlighted the need for better signposting to wider support, such as dementia charities, which could provide both emotional reassurance and practical advice to caregivers.

"[I needed] more support for me, as the carer, just to kind of feel less that I'm alone in the situation, just some reassurance... maybe that is where charities could come in." (Participant C12, Family Caregiver, Focus Group)

Inclusion and co-production

Inclusion in development

Many participants felt that the practical realities of dementia care were not sufficiently understood by those developing infection-control guidance. Some healthcare professionals spoke about how they thought it was not *"feasible"* (H6), *"practical"* (H5), or *"realistic"* (H10) to implement the COVID-19 guidance with patients living with dementia, particularly in care home settings where residents frequently walked around, required close contact, or were unable to understand isolation rules. Some felt this was because those developing guidance may lack experience in providing care to people living with dementia.

"It was just not possible on my floor with dementia, with the number of staff and the amount of people walking around, their guidance wasn't really realistic." (Participant H1, Senior Carer)

Participants expressed that there should be opportunities for healthcare workers to provide feedback on guidelines, to make the people developing guidance aware of some of the complexities involved in implementing guidance in settings with people living with dementia.

"The guidance was being dictated by people that were sitting in the offices, not seeing what's going on in the front line... that's why it's important to have people from the frontline [at] the table to help [make] the right decisions." (H5, care home director)

Digital exclusion

Finally, participants drew attention to the digital divide affecting many older adults and people living with dementia. Guidance that was predominantly available online was inaccessible for those without digital literacy or internet access. As one family caregiver put it,

"We should explore all channels to cater for people across all age groups... everybody doesn't use tablets or smartphones or the internet. That generation is still around, so we need to think of them as well." (Participant C20, Family Caregiver, Individual Interview)

Participants called for a multi-channel communication strategy that includes print, radio, and television to reach those excluded from digital sources. These accounts emphasised that equitable implementation depends not only on content, but also on dissemination routes that reach people in their everyday lives.

Discussion

This qualitative study explored how healthcare professionals and family caregivers received, communicated and adapted infection-related guidance for people living with dementia. Across three themes, participants described a recurring gap between the content of general recommendations and the realities of dementia care. Their accounts suggest that the usability of infection prevention guidance depends not only on the accuracy of its recommendations but also on whether it offers workable options for people with cognitive, behavioural and sensory needs. The findings are particularly relevant to geriatric care because infection prevention decisions occur alongside obligations to preserve dignity, relationships and emotional wellbeing.

The first contribution concerns translating national guidance into everyday care. Participants described guidance that changed frequently, arrived late or lacked dementia-specific detail. As a result, staff and families relied on their own judgement to interpret restrictions and communicate them to others. Similar difficulties with rapidly evolving guidance have been documented among care workers [9, 10]. Our findings highlight an additional problem: when recommendations do not describe feasible adaptations for dementia, responsibility for resolving uncertainty shifts to individuals who may have limited time or access to specialist support. This should not be interpreted as evidence that all local adaptations were unsafe; rather, it identifies an area in which clearer guidance and implementation support may be valuable.

A second contribution is the tension between infection risk and person-centred wellbeing. Family caregivers and professionals described situations in which isolation, visiting restrictions or face coverings caused distress or were difficult to explain to a person with dementia. Participants sometimes considered flexibility necessary to preserve wellbeing, particularly where restrictions disrupted familiar relationships or routines. Previous literature has reported psychosocial consequences of isolation and the importance of person-centred dementia care [11, 7, 15]. The present accounts suggest that future guidance should acknowledge these competing risks and offer clear, proportionate decision-making options, rather than assuming a single approach works for every individual. The interviews do not establish which adaptations would minimise infection risk, and clinical and public health assessments would be required to determine these options.

A third contribution concerns the format and dissemination of information. Participants valued short explanations, respectful language, visual or audio materials and opportunities to repeat information, but reported difficulty finding verified resources suitable for dementia care. Digital-only access and translation delays could compound these difficulties. The suggestion of a curated resource library is

therefore not simply a request for more leaflets: it reflects a need for reliable, accessible materials that can be located quickly and adapted without repeated duplication of work. Participants also called for frontline staff and people affected by dementia to be involved in guidance development. Co-production and usability testing are plausible next steps, although the present study did not evaluate their effectiveness [16, 17].

Strengths and Limitations

A strength of this study is its inclusion of complementary perspectives from 10 healthcare professionals and 10 family caregivers, with participants describing practical experiences across care homes and community settings. Reflexive thematic analysis allowed attention to the meaning and context of those experiences. Several limitations warrant consideration. Recruitment relied on a convenience sample, and the relatively small numbers within professional roles limit transferability to other services and populations. People living with dementia did not participate as interviewees, although people affected by dementia contributed to developing the caregiver interview guide through patient and public involvement. Interviews took place in 2024–2025 and relied on retrospective accounts of the pandemic, making recall and hindsight relevant. Individual interviews and a caregiver focus group may also have shaped what participants felt able to disclose. We did not measure infection outcomes, comprehension or the effectiveness of proposed adaptations, and recommendations should therefore be treated as hypotheses for future development and evaluation.

Implications for policy and practice

For geriatric services, the findings point to a need to treat accessibility and feasibility as integral to infection prevention guidance rather than as optional additions. Developers of national and local recommendations could provide concise versions alongside detailed clinical documents, make alternative formats available promptly and specify practical considerations for people who cannot understand or tolerate standard measures. In care homes, implementation support should include scenarios addressing isolation, visiting, personal care, and balancing infection protection with distress. Such guidance should be consistent with current clinical and public health requirements and should not be taken as permission to disregard essential precautions.

Communication training for professionals, access to trusted dementia-specific resources and consultation with families may help staff tailor explanations to individual needs. Participants' suggestions also support exploring a curated library of verified materials, available through both digital and non-digital routes, with clear ownership and processes for updating content. Future work should co-produce and test candidate resources with people living with dementia, family caregivers, care home staff and infection prevention specialists. Evaluation could examine acceptability, comprehension, implementation burden and the consequences for wellbeing and infection-related decision-making.

Conclusions

In this UK qualitative study, healthcare professionals and family caregivers described substantial practical challenges in applying general infection prevention guidance to dementia care. Participants often had to interpret and adapt information themselves while navigating cognitive and sensory needs, unfamiliar restrictions, and the risk of distress. These experiences show why dementia-inclusive communication requires attention to both the content of guidance and the circumstances in which it is used.

Future infection prevention planning should consider timely, accessible materials, feasible implementation options and the involvement of people affected by dementia and frontline professionals in guidance development. The proposed approaches warrant co-production and evaluation before claims can be made about their effects on adherence, wellbeing or infection outcomes.

Declarations

Ethics approval and consent to participate

- This study was approved by the Birkbeck, University of London Ethics Committee (reference 2324025) on 29 October 2024. All participants provided informed consent.

Consent for publication

- Participants consented to publication of anonymised interview quotations.

Competing interests

- The authors declare no competing interests.

Funding

- This work was supported by the UK Health Security Agency (Grant HE23-07). The role of the funder in study design, analysis and publication decisions should be confirmed by the authors.
- Availability of data and materials
- Interview transcripts are not publicly available because disclosure could compromise participant confidentiality. Requests for access are subject to ethics approval and author assessment.

Author Contribution

B.L. conducted participant recruitment, data collection, transcription and the primary qualitative analysis, and prepared the initial manuscript draft. J.A.C., E.J.D. and D.C. contributed to the study conception and design and jointly secured funding for the research. J.A.C. provided expertise in infection prevention and

public health and critically reviewed the manuscript. E.J.D. led the preparation and submission of the research ethics application, contributed to the methodological development and interpretation of the qualitative findings, and critically revised the manuscript. D.C. supervised the research, contributed to the interpretation of findings and critically revised the manuscript. All authors reviewed and approved the final manuscript.

Acknowledgement

We sincerely thank the healthcare professionals and family caregivers who generously shared their time and experiences to support this research. We are particularly grateful to the Patient and Public Involvement (PPI) group, including people living with dementia and their caregivers, for their valuable contributions to the development of the study materials. We also thank the wider COV-DEM project collaborators for their support and contributions to the research.

Data Availability

The datasets generated and analysed during the current study are not publicly available due to the potentially identifiable and sensitive nature of the qualitative interview data and the need to protect participant confidentiality. Anonymised excerpts supporting the findings are included in the published article. Further information about the study may be obtained from the corresponding author upon reasonable request.

References

1. Oliveira D, Bosco A, di Lorito C. Is poor health literacy a risk factor for dementia in older adults? Systematic literature review of prospective cohort studies. *Maturitas*. 2019;124:8–14. <https://doi.org/10.1016/j.maturitas.2019.03.010>.
2. Rostamzadeh A, Stapels J, Genske A, Haidl T, Jünger S, Seves M, Woopen C, Jessen F. Health Literacy in Individuals at Risk for Alzheimer's Dementia: A Systematic Review. *J Prev Alzheimer's Disease*. 2020;7(1):47–55. <https://doi.org/10.14283/jpad.2019.34>.
3. Eggenberger E, Heimerl K, Bennett MI. Communication skills training in dementia care: A systematic review of effectiveness, training content, and didactic methods in different care settings. *Int Psychogeriatr*. 2013;25(3):345–58. <https://doi.org/10.1017/S1041610212001664>.
4. Cassell JA, Middleton J, Nalabanda A, Lanza S, Head MG, Bostock J, Hewitt K, Jones CI, Darley C, Karir S, Walker SL. Scabies outbreaks in ten care homes for elderly people: A prospective study of clinical features, epidemiology, and treatment outcomes. *Lancet Infect Dis*. 2018;18(8):894–902. [https://doi.org/10.1016/S1473-3099\(18\)30347-5](https://doi.org/10.1016/S1473-3099(18)30347-5).
5. Liu N, Sun J, Wang X, Zhao M, Huang Q, Li H. The Impact of Dementia on the Clinical Outcome of COVID-19: A Systematic Review and Meta-Analysis. *J Alzheimers Dis*. 2020;78(4):1775–82.

<https://doi.org/10.3233/JAD-201016>.

6. Tahira AC, Verjovski-Almeida S, Ferreira ST. Dementia is an age-independent risk factor for severity and death in COVID-19 inpatients. *Alzheimer's Dement*. 2021;17(11):1818–31. <https://doi.org/10.1002/alz.12352>.
7. Suárez-González A, Rajagopalan J, Livingston G, Alladi S. The effect of COVID-19 isolation measures on the cognition and mental health of people living with dementia: A rapid systematic review of one year of quantitative evidence. *eClinicalMedicine*. 2021;39. <https://doi.org/10.1016/j.eclinm.2021.101047>.
8. Hanna K, Giebel C, Butchard S, Tetlow H, Ward K, Shenton J, Cannon J, Komuravelli A, Gaughan A, Eley R, Rogers C, Rajagopal M, Limbert S, Callaghan S, Whittington R, Shaw L, Donnellan W, Gabbay M. Resilience and supporting people living with dementia during the time of COVID-19; A qualitative study. *Dementia*. 2022;21(1):250–69. <https://doi.org/10.1177/14713012211036601>.
9. Bertini L, Bogen-Johnston L, Sadhwani S, Middleton J, Sharp R, Wood W, Roland D, Forder J, Cassell JA. (2023). Care Workers and Managers' Experiences of Implementing Infection Control Guidance in an Epidemic Context: A Qualitative Study in the South East of England, during the COVID-19 Prevaccination Era. *Health & Social Care in the Community*, 2023(1), 4127871 <https://doi.org/10.1155/2023/4127871>
10. Pilbeam C, Tonkin-Crine S, Martindale A-M, Atkinson P, Mablesen H, Lant S, Solomon T, Sheard S, Gobat N. How do Healthcare Workers 'Do' Guidelines? Exploring How Policy Decisions Impacted UK Healthcare Workers During the First Phase of the COVID-19 Pandemic. *Qual Health Res*. 2022;32(5):729–43. <https://doi.org/10.1177/10497323211067772>.
11. Masterson-Algar P, Allen MC, Hyde M, Keating N, Windle G. Exploring the impact of Covid-19 on the care and quality of life of people with dementia and their carers: A scoping review. *Dementia*. 2021;21(2):648–76. <https://doi.org/10.1177/14713012211053971>.
12. Mok, V. C. T., Pendlebury, S., Wong, A., Alladi, S., Au, L., Bath, P. M., Biessels, G. J., Chen, C., Cordonnier, C., Dichgans, M., Dominguez, J., Gorelick, P. B., Kim, S., Kwok, T., Greenberg, S. M., Jia, J., Kalaria, R., Kivipelto, M., Naegandran, K., ... Scheltens, P. (2020). Tackling challenges in care of Alzheimer's disease and other dementias amid the COVID-19 pandemic, now and in the future. *Alzheimer's & Dementia*, 16(11), 1571–1581 <https://doi.org/10.1002/alz.12143>.
13. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–57. <https://doi.org/10.1093/intqhc/mzm042>.
14. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Res Psychol*. 2021;18(3):328–52. <https://doi.org/10.1080/14780887.2020.1769238>.
15. Barbosa A, Sousa L, Nolan M, Figueiredo D. Effects of Person-Centered Care Approaches to Dementia Care on Staff: A Systematic Review. *Am J Alzheimer's Disease Other Dementias*. 2015;30(8):713–22. <https://doi.org/10.1177/1533317513520213>.

16. Moleman M, Macbeth F, Wieringa S, Forland F, Shaw B, Zuiderent-Jerak T. From getting things right to getting things right now: Developing COVID-19 guidance under time pressure and knowledge uncertainty. *J Eval Clin Pract.* 2022;28(1):49–56. <https://doi.org/10.1111/jep.13625>.
17. Meppelink CS, van Weert JC, Haven CJ, Smit EG. The Effectiveness of Health Animations in Audiences With Different Health Literacy Levels: An Experimental Study. *J Med Internet Res.* 2015;17(1):e3979. <https://doi.org/10.2196/jmir.3979>.
18. Altieri M, Santangelo G. The Psychological Impact of COVID-19 Pandemic and Lockdown on Caregivers of People With Dementia. *Am J Geriatric Psychiatry.* 2021;29(1):27–34. <https://doi.org/10.1016/j.jagp.2020.10.009>.
19. Blinka MD, Liu C, Sheehan OC, Rhodes JD, Roth DL. Family caregivers emphasise patience and personal growth: A qualitative analysis from the Caregiving Transitions Study. *Age Ageing.* 2022;51(2):afab266. <https://doi.org/10.1093/ageing/afab266>.
20. Braquehais MD, Vargas-Cáceres S, Gómez-Durán E, Nieva G, Valero S, Casas M, Bruguera E. The impact of the COVID-19 pandemic on the mental health of healthcare professionals. *QJM: Int J Med.* 2020;113(9):613–7. <https://doi.org/10.1093/qjmed/hcaa207>.
21. Braun V, Clarke V, Hayfield N, Davey L, Jenkinson E. (2022). Doing Reflexive Thematic Analysis. In S. Bager-Charleson & A. McBeath, editors, *Supporting Research in Counselling and Psychotherapy: Qualitative, Quantitative, and Mixed Methods Research* (pp. 19–38). Springer International Publishing https://doi.org/10.1007/978-3-031-13942-0_2
22. Burton A, McKinlay A, Dawes J, Roberts A, Fynn W, May T, Fancourt D. Understanding Barriers and Facilitators to Compliance with UK Social Distancing Guidelines During the COVID-19 Pandemic: A Qualitative Interview Study. *Behav Change.* 2023;40(1):30–50. <https://doi.org/10.1017/bec.2021.27>.
23. Gaigher JM, Lacerda IB, Dourado MCN. Dementia and Mental Health During the COVID-19 Pandemic: A Systematic Review. *Front Psychiatry.* 2022;13. <https://doi.org/10.3389/fpsyt.2022.879598>.
24. Gray KL, Birtles. Heather, Reichelt, Katharina, & and James, I. A. (2022). The experiences of care home staff during the COVID-19 pandemic: A systematic review. *Aging & Mental Health*, 26(10), 2080–2089 <https://doi.org/10.1080/13607863.2021.2013433>
25. Kazawa K, Kodama A, Sugawara K, Hayashi M, Ota H, Son D, Ishii S. Person-centered dementia care during COVID-19: A qualitative case study of impact on and collaborations between caregivers. *BMC Geriatr.* 2022;22(1):107. <https://doi.org/10.1186/s12877-022-02794-1>.
26. Kiljunen O, Savela R-M, Välimäki T, Kankkunen P. Managers' perceptions of the factors affecting resident and patient safety work in residential settings and nursing homes: A qualitative systematic review. *Res Nurs Health.* 2024;47(4):397–408. <https://doi.org/10.1002/nur.22382>.
27. Kruger LJ, Rodgers RF, Long SJ, Lowy AS. Individual interviews or focus groups? Interview format and women's self-disclosure. *Int J Soc Res Methodol.* 2019;22(3):245–55. <https://doi.org/10.1080/13645579.2018.1518857>.

28. Mansutti I, Achil I, Rosa Gastaldo C, Tomé Pires C, Palese A. Individuals with hearing impairment/deafness during the COVID-19 pandemic: A rapid review on communication challenges and strategies. *J Clin Nurs*. 2023;32(15–16):4454–72. <https://doi.org/10.1111/jocn.16572>.
29. Rajagopalan J, Arshad F, Hoskeri RM, Nair VS, Hurzuk S, Annam H, Varghese F, Dhiren BRR, Ganeshbhai SR, Kammammettu PV, Komaravolu C, Thomas S, Comas-Herrera PT, A., Alladi S. Experiences of people with dementia and their caregivers during the COVID-19 pandemic in India: A mixed-methods study. *Dementia*. 2022;21(1):214–35. <https://doi.org/10.1177/14713012211035371>.
30. Schroeter ML, Kynast J, Villringer A, Baron-Cohen S. Face Masks Protect From Infection but May Impair Social Cognition in Older Adults and People With Dementia. *Front Psychol*. 2021;12:640548. <https://doi.org/10.3389/fpsyg.2021.640548>.
31. Wittenberg R, Hu B, Jagger C, Kingston A, Knapp M, Comas-Herrera A, King D, Rehill A, Banerjee S. Projections of care for older people with dementia in England: 2015 to 2040. *Age Ageing*. 2020;49(2):264–9. <https://doi.org/10.1093/ageing/afz154>.
32. Wójcik D, Szczechowiak K, Konopka P, Owczarek M, Kuzia A, Rydlewska-Liszkowska I, Pikala M. Informal Dementia Caregivers: Current Technology Use and Acceptance of Technology in Care. *Int J Environ Res Public Health*. 2021;18(6). <https://doi.org/10.3390/ijerph18063167>. Article 6.
33. Zimmerman S, Sloane PD, Hickey JS, Wretman CJ, Gizlice SP, Thomas KS, Carder P, Preisser JS. Dementia and COVID-19 infection control in assisted living in seven states. *J Am Geriatr Soc*. 2022;70(9):2653–8. <https://doi.org/10.1111/jgs.17923>.

Figures

Figure 1

Recommendations for adapting health guidance for people living with dementia

	Recommendations	Things to avoid
 Language	• Use simplified language • Present information in short sentences, bullet points, or short paragraphs • Provide information in other languages	• Making information patronising • Using medical terminology or acronyms
 Format	• Use images to aid in understanding • Create videos that are engaging • Be mindful of visual and hearing deficits when creating resources	• Providing health information in only one format, language, or only online • Using childish images in resources for adults living with dementia
 Respect	• Include people affected by dementia in the creation of resources to ensure they are appropriate and relevant to that population	• Assuming that a person with dementia is incapable of understanding health guidance without trying to explain it to them

Figure 1

See image above for figure legend

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [CovDEMSupplementaryMaterial.docx](#)