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The Importance of the Social Environment for People Living With Dementia and Their Carers: Qualitative Evidence From DETERMIND and PriDem on the Impact of COVID-19 Service Changes and Restrictions in England and Wales

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Abstract

This paper presents evidence from multiple perspectives on the impact of changes to health and social care service delivery, and the related social environment, for people living with dementia and their carers during the COVID-19 pandemic. Qualitative interview data from 130 people living with dementia, family carers and health and social care professionals in England and Wales were collected for the DETERMIND and PriDem studies during the height of the COVID-19 pandemic (2020–2021). These were analysed abductively by members of both teams, applying the lens of person-centred dementia theory. The lack of in-person social and professional contact was of great concern during the pandemic to people living with

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dementia, family carers and health and social care professionals. Our overarching finding that service changes degraded the social environment of the person living with dementia had five sub-themes: (1) A state of limbo; (2) Social environment overlooked as a priority; (3) Effects on family carers; (4) Tensions between a medical versus person-centred approach; (5) Maintaining or regaining a focus on personhood. Crosscutting these was a risk that people who were already disadvantaged by isolation and impairment were most affected by service changes. Pressures on carers to facilitate and/or directly provide social stimulation in the absence of previous opportunities might explain the concurrent deterioration of carers' quality of life. Professionals worked hard to find ways to tailor support and facilitate social contact within the limits of pandemic restrictions, demonstrating that this is possible and should be prioritised. A further suggestion was to delineate dementia social groups as 'necessary care' in future, given their importance to the wellbeing of people living with dementia and their carers. We conclude that person-centred delivery can be achieved in even the most challenging of circumstances and should be a core consideration of future planning for crises, prioritising social wellbeing alongside medical need.

Keywords
dementia, family carers, COVID-19, person-centred, service delivery, social groups, health care, social care, remote provision, social isolation

Background

At the start of the COVID-19 pandemic in England and Wales, many difficult decisions were made which had significant (intended and unintended) consequences for people's health and wellbeing. Public health emergency policy mandated lockdowns, travel restrictions, and the closure or remote delivery of non-essential health and social care services to limit in-person contact (Wheatley et al., 2022). A series of early papers highlighted potentially negative impacts of service changes and enforced isolation for people living with dementia and their carers (Giebel, Cannon, et al., 2021, Giebel, Pulford, et al., 2021; Glassner et al., 2022; Liu et al., 2021; O'Rourke et al., 2021; Roach et al., 2021; Talbot & Briggs, 2021). One of the unintended consequences flagged in these papers was the potential for social isolation to have a particularly negative impact. Subsequent international studies have indicated accelerated cognitive decline during the pandemic for people living with dementia, (Ismail et al., 2021; Joo et al., 2022; Matsuzono et al., 2024; Tondo et al., 2021). Some studies also observed a decline in carer quality of life (Hicks et al., 2022; Perach et al., 2023; Read et al., 2024).

Not all studies observed declines in wellbeing during the pandemic, however, (Dixon et al., 2022; Gamble et al., 2022; Sabatini et al., 2022) suggesting a nuanced picture worthy of further exploration. Work published early on was, by necessity, rapidly conducted. Quantitative studies were largely cross-sectional (Suárez-González et al., 2021) and qualitative evidence tended to focus on the views and experiences of just one group - either family carers (Harris & Titler, 2022; Tulloch et al., 2022), health care workers (Scerri et al., 2022; Wheatley et al., 2022) or people living with dementia (Glassner et al., 2022). DETERMIND and PriDem were two longer-term dementia research programmes collecting and analysing data before and throughout the COVID-19 pandemic. The overall aim of DETERMIND was to understand factors contributing to inequities in care and outcomes for people living with dementia over time (Farina et al., 2020). PriDem focussed on primary care-led post-diagnostic dementia care, using qualitative interviews with dementia care staff from a range of sectors and services across England and Wales (Wheatley et al., 2021). Data from both DETERMIND and PriDem provide a rich source of evidence about service changes during COVID and their nuanced implications. PriDem has published evidence suggesting that professionals were concerned about the potential impact of service changes on the wellbeing of people living with dementia and their carers (Wheatley et al., 2022). The PriDem and DETERMIND teams have since been working together to conduct further analysis combining evidence from the PriDem professional interviews and DETERMIND interviews with people living with dementia and family carers. This collaborative work has been informed by theory on personhood and the role of the social environment in the wellbeing of people living with dementia and their carers.

Dementia, Personhood and the Social Environment

Infrequent social contact is one of 14 risk factors for dementia (Livingston et al., 2024) and availability of enriching social opportunities was identified by the pan-European network, INTERDEM, as a key influence on people living with dementia's wellbeing (Dröes et al., 2017). Kitwood's theory of malignant social psychology helps explain the relationship between social environment and cognitive wellbeing, identifying multiple ways in which the actions of others could deny people living with dementia a sense of personhood, including: *disempowerment, invalidation, banishment, ignoring, withholding, disruption and disparagement* (Kitwood, 1997). Kitwood argued these factors could measurably impact the wellbeing and cognition of people living with dementia, with the implication that a more positive social environment, involving person-centred interactions and meaningful occupation, could slow deterioration and promote wellbeing. This principle has been widely accepted in dementia studies (Brooker, 2022; Brooker & Latham, 2015; van Dijk et al., 2012; Downs et al., 2006; Metzelthin et al., 2024; Thijssen et al., 2023) with recent application in reablement theory (Metzelthin et al., 2024) and music therapy (Kelly et al., 2023). Threats to personhood therefore provide a possible explanation for reduced wellbeing for many people living with dementia during COVID-19, including reports of accelerated cognitive decline, as social distancing rules and the pausing of services led to enforced isolation for many.

The social environment and access to related services has also been shown to influence the wellbeing of dementia carers (Aledeh & Adam, 2020; Robertson et al., 2024). During COVID, evidence suggests that co-residency with the person living with dementia influenced how carers coped with caring (Colclough et al., 2023). The decrease in carer quality of life observed quantitatively by DETERMIND during COVID-19 was greatest in those supporting people with more severe dementia, those in deprived areas, and those where memory services had withdrawn support (Hicks et al., 2022). Application of dementia theory may help us to understand these trends, recognising the interdependence of people living with dementia and their carers (Rapaport et al., 2020).

This paper draws together qualitative evidence collected through DETERMIND and PriDem, combining three separate datasets spanning the first 22 months of the coronavirus pandemic. Informed by dementia theory, we considered the impact that service changes had on the social environment of people living with dementia and family carers, and the consequences of these from different perspectives. The overall aim was to reflect on, and communicate, learning that could be applied in future emergency situations.

Methods

We conducted reflexive thematic analysis (Braun & Clarke, 2021) of qualitative interview data from three datasets collected for two studies underway during the COVID-19 pandemic (2020–2021) in England and Wales:

PriDem. was a 5-year study exploring the views and experiences of commissioners, managers, and frontline staff working in post-diagnostic dementia services across England and Wales using remote qualitative interviews (Wheatley et al., 2021). Ethical approval for PriDem was granted by NHS Research Ethics Committee Wales 3 (reference 18/WA/0349).

DETERMIND. was a 6-year, mixed-method cohort study focussed on quality of life and inequalities for people newly diagnosed with dementia and their carers (Farina et al., 2020), recruiting from three areas of England (the South East, North East and London). This had several qualitative strands, including one (DETERMIND-WS4) focussing on social care service use and another (DETERMIND-C19) exploring the experiences of people living with dementia and their carers during COVID-19. Ethical approvals for the DETERMIND-WS4 and DETERMIND-C19 studies were obtained by the HRA Brighton and Sussex Research Ethics Committee (REC 19/LO/0528. IRAS 261263).

Recruitment and Data Collection

PriDem. Professionals recruited to the PriDem study (before the COVID-19 pandemic) who had given permission for follow-up contact were invited to take part in the PriDem-C19 study. A purposive target sample size of 20 was adopted to reflect varied experiences from a range of sectors, service types and geographical locations across England and Wales without placing undue burden on services. Data were collected by two researchers by telephone or video-call between February and May 2021 (i.e. after at least a year of pandemic and associated lockdowns in the UK).

DETERMIND-C19. A sample of people living with dementia, and a separate sample of carers, were purposively selected from the DETERMIND cohort, covering a range of demographic and personal characteristics. Participants with dementia were all diagnosed within the previous 14 months and had capacity to give informed consent. Qualitative interviews were conducted in the first winter of COVID in the UK, between October 2020 and January 2021 by three interviewers over the telephone or by video-call. Interviews were steered by a topic guide covering access to services, challenges, coping mechanisms and perceived outcomes.

DETERMIND-WS4. A different sample of people living with dementia and their carers was selected from the DETERMIND cohort focussing on people currently using social care services and those who were paying, or may in future need to pay, for social care. Potential participants were invited as dyads or as individuals. Again, variation in personal and demographic characteristics was sought. Topics for DETERMIND-WS4 included experiences of diagnosis, care and support, care-coordination, planning for future care needs, and outcomes. Exploring these topics meant discussing COVID-19 related changes to service delivery and their impact given the timings of the interviews, which spanned the first 22 months of the pandemic, with a sub-sample of participants taking part in annual follow-up.

Quotes from all three sub-samples are labelled with the month of the interview to indicate the time point they refer to, recognising that the context changed considerably over the first two years of the pandemic in the UK.

Analysis

Data were analysed abductively (Thompson, 2022), with the findings of initial (separate) analysis further developed collaboratively, broadly applying the lens of personhood (Kitwood, 1997) and, more specifically, in relation to the importance of the social environment for supporting psychological needs (Brooker & Latham, 2015).

Whilst data for each study were managed separately (with no personal data shared between teams), each team used a similar approach to initial analysis. Both teams started with inductive thematic analysis and worked reflexively (Braun & Clarke, 2021, 2022), linking with wider team members to bring in multiple perspectives and reduce the influence of any one researcher (Shenton, 2004). Coding schemes and narrative summaries were then shared between teams with similarities and differences discussed in cross-team meetings to develop overarching themes and sub-themes collaboratively. Through team discussions, links between our findings and wider dementia theory and literature were developed. Our final findings were agreed deliberatively through a series of cross team online meetings, email and one face-to-face meeting.

Findings

In total, qualitative data from 130 people living with dementia, family carers and health and social care professionals contributed to the findings presented here.

PriDem

21 health and social care professionals from primary, secondary and social care and the third sector were interviewed, with professional backgrounds covering general practitioner (GP), dementia specialist nurse, occupational therapist (OT) and dementia support worker (Table 1). Services included memory assessment services, community dementia teams and specialist support services for black, Asian and minority ethnic (BAME) people and people with young onset dementia. Interviews lasted on average 34 minutes.

Table 1. Key Characteristics of PriDem Participants

Role and characteristics	*n* (*N* = 21)
Role	
Commissioners	6
Service managers/team leads	8
Frontline staff	7
Sector	
Primary care	6
Secondary care	9
Joint health and social care	1
Third sector	5
Region	
London	5
Midlands	1
North East and Yorkshire	5
North West	2
South East	3
South West	2
Wales	3
Gender	
Female	14
Male	7

Table 2. Characteristics of DETERMIND-C19 Participants With Dementia

Characteristics	*n* (*N* = 21)
Age	
<65	1
65–74	6
75–84	10
≥85	4
Gender	
Female	12
Male	9
Ethnicity	
White British	18
Indian	1
Mixed ethnic background	1
Other ethnic group	1

DETERMIND-C19

21 people newly diagnosed with dementia (Table 2), and 42 carers (Table 3) were interviewed. The interviews lasted, on average, 55 minutes.

DETERMIND-WS4

16 people living with dementia (Table 4) and 30 carers (Table 5) were interviewed. The interviews lasted on average 48 minutes.

Table 3. Characteristics DETERMIND-C19 Family Carer Participants

Characteristics	*n* (*N* = 42)
Age	
20–34	2
35–49	3
50–64	13
65–79	17
≥80	7
Gender	
Female	32
Male	10
Ethnicity	
Asian (unspecified)	1
Caribbean	1
Indian	1
White/Black African	1
White/Black Caribbean	1
White British	37

Table 4. Characteristics of DETERMIND-WS4 Participants With Dementia

Characteristics	*n* (*N* = 16)
Age	
<65	1
65–74	3
75–84	11
≥85	1
Gender	
Female	9
Male	7
Ethnicity	
White British	10
Indian	1
Pakistani	1
Caribbean	1
Other ethnic group	2
Any other White background	1

Overarching Finding: Service Changes Degraded the Social Environment. Practitioners interviewed for PriDem were concerned that people living with dementia faced major barriers to accessing both general services such as GP appointments, and specialist dementia services. The closure of social groups and activities was of particular concern, as were shifts from face-to-face to remote provision. Facilitating remote access to services and groups was challenging, and whilst practitioners were innovative in their attempts to include people, solutions that relied on family carers risked further

Table 5. Characteristics DETERMIND-WS4 Family Carer Participants

Characteristics	*n* (*N* = 30)
Age	
20–34	1
35–44	1
45–54	4
55–64	11
65–74	6
75–84	6
≥85	0
Missing	1
Gender	
Female	21
Male	9
Ethnicity	
White British	26
White and Black Caribbean	1
Any other mixed/Multiple ethnic background	1
Any other White background	1

distancing professionals from the person living with dementia and excluding those without a family carer.

Interviews for DETERMIND indicated that, whilst some people living with dementia managed well and found ways to navigate restrictions and new challenges, others felt isolated and unsupported without face-to-face contact and opportunities for social engagement. Family carers (themselves struggling with the contraction of formal and informal support) were substantially affected, finding themselves the key people responsible for maintaining the social environment of the person they cared for.

This overarching finding, that service changes degraded the social environment of the person living with dementia, has five sub-themes: (1) A state of limbo; (2) Social environment overlooked as a priority; (3) Effects on family carers; (4) Tensions between a medical versus person-centred approach; and (5) Maintaining or regaining a focus on personhood. Crosscutting these was the risk that people already disadvantaged by isolation and impairment were most likely to be affected by service changes.

A State of Limbo.

During the first year of the pandemic, ‘essential’ health services were maintained, albeit with restrictions. However, many NHS dementia services (including memory services) were not considered essential. Similarly, post-diagnostic dementia support, commonly provided by social care and voluntary sector organisations, was not classed as essential and delivery was generally paused or switched to remote contact.

Professionals observed that service interruptions left families in a state of limbo. Closures of memory services, for example, meant there were long delays in receiving dementia diagnoses. In the meantime, people received little information and were unable to access certain types of post-diagnostic support. Professionals worried that it could be distressing for people living with dementia and their family members not to know if or how they might be eligible for services at this time. People living with dementia and their families confirmed that the extended service interruption created a void and associated sense of limbo:

> A: ...she had a brain scan in March… and then of course we heard nothing because of the lockdown and everything else; normally she would have been diagnosed I think probably by about April/May time, but yeah, we had to wait until December for the diagnosis….
>
> Q: Right. So that, that period, March to December, was there anything, anything in that part, any support?
>
> A: No, none at all.
>
> (Carer, WS4, November 2021)

Carers of people who were newly diagnosed described a vicious circle whereby the lack of contact with services meant there was no way of knowing what support might be available or how to access this.

> Q: Is there any help you’d have wanted?
>
> A: I suppose a sort of clear, clearer view of what the system was and, and what I should do to support her, and at what point I could say, look, this doesn’t work, you know. But because we were in lockdown… it was really difficult to know how I could involve Social Services or doctors or what because they weren’t available anyway and were refusing to do home visits.’
>
> (Carer, WS4, September 2021)

Practitioners were concerned about people living with dementia getting lost in the system or missing their chance for support, resulting in early admission to long-term care or even reaching the end of their life without appropriate services and support. This was thought especially likely for people living alone without regular carer support. DETERMIND interviews with people without a co-resident carer confirmed that some had not had any service contact since the start of the pandemic. Two such participants moved into residential care with significant needs less than 12 months after their initial interviews (at which they had both reported managing independently), indicating a rapid decline that might have been mitigated with more proactive support.

Social Environment Overlooked as a Priority. The importance of social groups to the wellbeing of people living with dementia and their carers was thought to have been underestimated during the pandemic. Government rules did not recognise the special importance of the social environment to maintaining the cognitive wellbeing of people living with dementia, which meant that dementia services and groups were not considered essential provision, particularly in the initial lockdown. The voices of those struggling most were likely not captured by research conducted during the heart of the lockdowns because of the necessary reliance on remote data collection methods and use of digital technology. However, data from a number of our telephone interviews highlighted that some people living with dementia experienced considerable isolation as a result of closed social groups. The resultant lack of opportunity to participate in valued activities had a detrimental impact on wellbeing, skills and confidence which increased as the isolation persisted, with clear digital inequalities evident:

> No, I'm not online, I'm not on the computer.... I just can't, can't fathom out... I've been shown but I just forget each time. So, I just leave it.
>
> (Person living with dementia, C19, October 2020)

Even for individuals in residential settings isolation became a strong narrative, in the below example because restrictions on visiting were compounded by group activities stopping:

> Q: ...has it affected your wellbeing at all do you think these groups stopping?
>
> A: Yeah, mentally it has, or physically; well it might have done physically actually... Because I'm not doing the exercising, yeah… [and] I've been depressed... Because I've been on, on, on my own for so long, yeah, and I see very few people now at the moment...
>
> (Person living with dementia, WS4, September 2021)

One professional noted that being isolated could be '*clinically bad for the brain*' and some believed that reduced social stimulation had had the *most* significant impact on people living with dementia during the pandemic:

> So, support networks have reduced significantly, their routines, their structures, the way they would have worked and functioned together, to help them cope with living with dementia, is depleted. So, not [only] are you not being able to see your family, you're not able to get access to your groups, your activities, it's multi-factorial.
>
> (Specialist nurse, PriDem, April 2021)

The same issues were echoed by carers, with some concerned that the people they cared for were deteriorating past a point where they would be able to re-join groups or activities when restrictions lifted.

There was some evidence of people living with dementia developing new skills and friendships during the lockdowns, or staying in touch with different communities using digital technology:

> …under the lockdown I have, I attend an afternoon religious meeting ... I look forward to it every afternoon... I also have regular Zoom meetings with my college mates from the medical school of fifty years ago ... that's started in lockdown.... it is wonderful...
>
> (Person living with dementia, WS4, July 2020)

Nevertheless, overall there was a strongly stated preference for face-to-face social contact, even from those who could use digital technology. In particular it was noted that the value of many groups had stemmed from the nature of the social environment they created, which did not always transfer to online delivery:

> [The dementia club started using Zoom and] it got a bit wishy-washy, you know, it was the same people and few people turned up, and we did quizzes and it was okay, they were trying [but] their strength was creating this environment ... so a Zoom, you know is a little more difficult.
>
> (Carer, C19, January 2021)

Effects on Family Carers. Some carers explained they had become the sole source of social stimulation for the person living with dementia they cared for, with wider visits from family and friends severely limited and supportive social settings such as dementia cafes (which can offer carer respite) closed:

> Well I've been pretty much doing everything, it's the relentlessness of COVID that's made it more difficult, not my mother…
>
> (Carer, WS4, June 2021)

Professionals articulated concern that the reliance of people living with dementia for social stimulation on family carers, without respite from formal services or wider social networks, could result in carer burnout. Several noted that carers had tried to cope past the point of being able to do so, with initial resilience eroding over time:

> Families initially were probably quite resilient and were quite - I heard, "Well, we lived through the war once," I've heard many times, "We can do this" but I think because there is no kind of end date to it as things went on, and as we went into second lockdown, third lockdown, families were just really, really tired. People were often either going into crisis for one reason or another.
>
> (Specialist nurse, PriDem, February 2021)

Efforts to help people living with dementia adapt to the circumstances of the pandemic, such as the use of digital communication technology, also generally involved an increased reliance on family support.

> The singing for the brain group is still running, you know, with [charity], they are quite good. But that they can only reach people who are tech savvy and have got a computer, or maybe they have got a family member that can set up.
>
> (Dementia support worker, PriDem, February 2021)

The risk here was twofold, as those who were less able to use digital technology due to cognitive impairment and/or lack of a co-resident carer to help them online were more likely to be excluded, whilst in situations where there was a carer available to provide such support the person living with dementia's social inclusion became heavily reliant on the involvement of the carer, adding pressure to an already pressurised situation.

Tensions Between a Medical versus Person-Centred Approach. Professionals seemed generally attuned to, and empathetic about, the impact of service changes on people living with dementia and family carers. They recognised that people were frightened, overburdened, lacking in social contact and support, and sometimes deteriorating physically and mentally as a result. They also recognised that they probably only saw the tip of the iceberg and that understanding the world from the perspective of the person required a greater leap of imagination than before because of their reduced in-person contact:

> So you would imagine that, after a year, most people will be struggling and most people will be saying, "It has been awful." The patient has deteriorated, they have lost their skills. The carer will be absolutely exhausted… We know that only from the people we have asked, so can you imagine all the people who have not asked and we have not seen? I mean, some people just have not seen anybody and we do worry about that.
>
> (Memory service manager, PriDem, February 2021)

Despite these person-centred concerns, the practicalities of managing in a crisis appeared to have necessitated a shift towards a more medicalised approach. In memory clinics, professionals reported diagnosis being led by clinical staff, with less focus on multi-disciplinary working, compromising opportunities for a holistic approach. Remote communication was considered more convenient by some, but receiving a life changing diagnosis over the telephone could be de-personalising:

> 'that is when we got [the diagnosis] by phone, which of course is very difficult for somebody in [husband's] position, but by phone…'
>
> (Carer, WS4, November 2021)

In social care, some staff noted a similar shift away from personalisation. The core social care offer was maintained, but it was harder to tailor support to ensure it met individuals' needs:

> 'It's been very hard for people to get probably the tailored support they would have got in 2019. They still have access to social care, they would have been able to get assessment, but it tends to be traditional services, like home support packages or needing urgent respite.'
>
> (Specialist nurse, PriDem, April 2021)

Carers felt this lack of personalisation keenly, particularly at points of transition, for example, moves to residential care, respite, or hospital. Professionals said they took a trial-and-error approach to enable people to access something rather than nothing, aware that approaches were untested and there may be unintended consequences. One GP, for example, described how their practice had decided to place all people living with dementia on the 'shielding list' (meaning they were considered to be Clinically Extremely Vulnerable to COVID-19), see (NHS England).[1] This was done with anticipated benefits to patients, who would receive prioritised access to support and resources (e.g. shopping slots) but may have had the unintended consequence of further reducing social contact and making some people more reluctant to re-engage with friends and services once restrictions were eased.

There was a view from professionals that the voices of people living with dementia were being lost to services: both through the lack of direct contact, and the reliance on carers to facilitate contact. Where people lived alone, professionals were concerned that the lack of in-person contact meant there were fewer opportunities for people to self-advocate. For people with a family carer living with or regularly supporting them, there was concern that an over-reliance on the carer to advocate for the person and facilitate communication could disconnect services from the person they were primarily there to support.

Professionals were also concerned that families of people who had moved to residential care and hospital settings were being disconnected from them. The right for family carers to continue supporting people living with dementia in healthcare and hospital settings had been long fought for, recognising the value of carers' first-hand knowledge of the person's needs and wishes, but during COVID-19 this right was initially lost. In care homes, the 'essential caregiver' role was eventually established, although this was not universally adopted and there were related challenges such as deciding which family carers could be 'essential caregivers' and how they should be supported.

Maintaining or Regaining a Focus on Personhood. Some professionals described how opportunities for providing person-centred care had emerged during the pandemic, for example, when reconnecting with families to re-assess their needs in response to changing restrictions. The focus tended to be general welfare and wellbeing rather than dementia-specific support or social environment, but nevertheless emphasised the value of the person:

> …the other day-centres have more gone to supporting their normal attendees in different ways. It might be just calling in on them, seeing if they need help with shopping and things, or they've been keeping in touch with the newsletter or whatever.
>
> (General Practitioner, PriDem, February 2021)

A personal approach was greatly valued by people living with dementia and their carers, and proactive 'checking-in' calls were particularly well received. A carer, for example, described on-going telephone contact from their dementia hub as *'marvellous'*. Having a named contact person and/or the phone number of a professional to call upon if needed was similarly reassuring, especially where people living with dementia were also living with serious co-morbidities, such as cancer.

Some professionals described working hard, within the limits of government restrictions, to continue to provide support tailored to the preferences and needs of people living with dementia, for example, by arranging home visits in the garden or going for a walk with the person rather than entering the house wearing PPE (personal protective equipment), which some people living with dementia could find unsettling.

> …if you're building up a relationship and trying to build trust, that it was actually easier, sometimes, even to go outside and walk with a client than to try and do it online or by telephone. Particularly if it was that first contact.
>
> (NHS commissioner, PriDem, March 2021)

Some healthcare professionals felt remote provision had created new opportunities to be person-centred and inclusive, for example by reaching people in rural or less well-served locations or by including more distant family members in online-meetings. Use of remote communications could also facilitate peer-group contact across the country, such as groups of people with young onset dementia or a particular diagnosis.

Nevertheless, the lack of options for in-person social and professional contact was the greatest concern for professionals, carers and people living with dementia overall. One solution suggested was to delineate dementia groups as *necessary care* rather than 'a social event', something this commissioner had taken steps to emphasise with colleagues:

> So people tend to interpret what they can and can't do with those groups and activities according to the regulations that govern our social lives. So in the same way as I can't go to the pub [because of COVID restrictions] and see my friends, [services] will think, "I can't organise this group for people with dementia". And I've done quite a lot of emailing out and raising awareness of the provision for support groups to be able to meet [as necessary care].
>
> (Joint health and social care commissioner, PriDem, February 2021)

Discussion

Early evidence on the effects of lockdown restrictions and service changes suggested a particularly detrimental impact on the wellbeing of people living with dementia (Giebel et al., 2021a, 2021b; Glassner et al., 2022; O'Rourke et al., 2023; Roach et al., 2021; Talbot & Briggs, 2021) and on carer quality of life (Giebel et al., 2023; Hicks et al., 2022; Read et al., 2024). Dementia theory posits a potential causal mechanism for this; the need for social stimulation to maintain wellbeing and slow cognitive decline (Kitwood, 1997), something that is empirically supported (Sommerlad et al., 2019). It also provides a possible explanation for the impact on family carers, who became solely responsible for maintaining people's social wellbeing in a restricted social environment, with minimal support from formal services. Our findings support the application of this theory, showing the isolating effects of service closures and adoption of remote delivery modes, particularly for those with the greatest needs for inclusion (living alone, or with more severe dementia affecting capacity to engage with digital communication). Some professionals identified reduced social stimulation as the most significant factor affecting people living with dementia at this time, believing that this had been severely underestimated. The effect was two-fold: restrictions and changes to service delivery distanced people living with dementia from social support; and at the same time increased pressure on carers to be their bridge to the outside world. Interviewees noted that the voices of many people living with dementia went largely unheard at this time, due to a lack of direct service contact and greater reliance on carers to facilitate communication with professionals. Individual professionals worked hard to overcome these challenges, against a backdrop of increasingly medicalised, less person-centred delivery, blanket mitigations and prioritisation of 'essential' services. One lesson may be that social groups and related support should be classed as 'essential' to the health and fundamental wellbeing of people living with dementia and, by extension, their carers.

These findings are consistent with those of other studies conducted during COVID-19. For example, Daley et al. (2022) found reduced social interaction was the main cause of reduced quality of life for people living with dementia, and the perceived impact of this on the cognition of the person living with dementia was, in turn, a key factor in influencing the wellbeing of family carers. In DETERMIND quantitative analyses, the most notable declines reported by carers were in their abilities for 'Meeting the personal needs of the person living with dementia' and overall 'Carer well-being' (Read et al., 2024). Our combined qualitative analysis supports the suggestion that reductions in carers' quality of life were linked to their difficulties meeting the needs of the person living with dementia within a severely reduced service system, and in particular to offer or provide access to social stimulation.

Some studies have highlighted factors that appeared to moderate negative impacts of lockdowns, such as regular checking-in (O'Rouke et al., 2021). It has also been noted that some people living with dementia did not passively accept their circumstances but instead worked to support their own well-being (Dixon et al., 2022; Glassner et al., 2022). The IDEAL (Sabatini et al., 2022) and DETERMIND quantitative findings showed maintenance of health-related quality of life for people living with dementia (but not carers) over time (Hicks et al., 2022; Read et al., 2024). Overall, however, there is considerable evidence that the pandemic had a disproportionately negative impact on people living with dementia and their carers (Burns & Howard, 2021; Hazan et al., 2023 ; Masterson-Algar et al., 2022). More than a quarter of those who died in the UK in the first four months of the pandemic had a diagnosis of dementia (despite comprising just 2% of the adult population) and 82% of people living with dementia surveyed by the Alzheimer's Society over this time reported deterioration in their symptoms (Alzheimer's Society, 2020). Studies have also shown that cognitive impairment declined significantly more rapidly during the pandemic than in pre-pandemic times (Ismail et al., 2021; Joo et al., 2022; Matsuzono et al., 2024; Tondo et al., 2021).

Our theoretically informed qualitative analysis suggests that the impaired social environment, reduced opportunities for occupation and the resultant pressures on carers all contributed to these negative impacts. Further, whilst it might have been expected that the end of restrictions would lead to a bounce-back in wellbeing for carers, longitudinal evidence from quantitative DETERMIND data suggest that this did not happen (Read et al., 2024). Giebel, Cannon, et al. (2021) flagged a risk that people living with dementia might miss their opportunity to re-join groups and return to valued activities once restrictions lifted, a concern reflected in some of our interviews. This raises the possibility that some of the impacts discussed in our study may not be easily reversed or mitigated for later. This could be a particular risk for those newly diagnosed at the start of the pandemic who may have missed out on vital routes into timely support, something which could be explored in future analysis of data from samples recruited pre and post COVID lockdown.

Strengths and Limitations

Combining data from three separate qualitative studies, each with purposive, maximum variation samples, meant we could consider and contrast the experience of dementia care and support during the pandemic from multiple perspectives. Moreover, as we were already in contact with participants with dementia and their carers for DETERMIND, we were not reliant on convenience sampling or digital recruitment methods, and were more likely to have included those who might have been otherwise excluded. A further strength of DETERMIND was the longitudinal perspective, with qualitative data gathered from people living with dementia and carers throughout the first 22 months of the pandemic, enabling exploration of temporally situated experience in a way that cross-sectional studies were unable to do. Our sample did, nevertheless, have limitations. While we were able to include some participants from minority ethnic groups, our samples did not allow for separate analysis of their experiences. Research by West et al. (2021) found that social isolation was an important factor in the experience of black and Asian people living with dementia during the pandemic, suggesting this is an area in need for further attention. Similarly, whilst we did interview people living with dementia identifying as LGBTQ+, small numbers did not allow for separate analysis. A linked DETERMIND study has flagged that this population are more likely to live alone, with less family contact (Hammond et al., 2024), which may have implications for how they managed during the pandemic given our findings on the significance of these factors, again, pointing to the need for further research.

Wider Policy Context and Implications

Dementia theory about the importance of social factors on wellbeing has long been influential in the development of interventions designed to limit the negative impacts of dementia (Brooker & Latham, 2015; Downs et al., 2006; Kelly, 2010; Kitwood, 1997; Metzelthin et al., 2024; Thijssen et al., 2023; van Dijk et al., 2012). The evidence presented in this paper supports the application of this theory in understanding the impact of COVID-19 and associated restrictions on people living with dementia and their carers, and emphasises the necessity of positive social contact. Bartlett and O'Connor (2007) drew upon the concept of citizenship to broaden the personhood lens and an emerging literature following this has highlighted the rights of people living with dementia as active citizens (Kelly & Innes, 2013), incorporating dementia within wider models of disability (Butchard & Kinderman, 2019; Cahil, 2018; Shakespeare et al., 2019; Thomas & Milligan, 2018). At the same time, a rights-based movement has arisen, led by people living with dementia, to organise and publish literature on their rights (drawing on international human rights legislation) to be: actively involved in decision making; supported to participate in society; and to receive care and support that meets their needs whilst being recognised and respected as partners in that care (Boyle, 2010; DEEP, 2012; Dementia Alliance International, 2016; European Working Group of People with Dementia, 2012; McCabe & Bradley, 2012). Despite these developments, the policy required to underpin and propel progress in dementia care had lost momentum *before* the pandemic (Britton & Zimmermann, 2022), with the Prime Minister's Challenge on Dementia in 2015 representing the last major strategic policy development in England (Department of Health, 2015). Britton and Zimmermann (2022) view the crisis of dementia care during the COVID-19 pandemic in this wider context, arguing that it fits a longer-term pattern of 'cure eclipsing care' in dementia policy. The waning policy context pre-pandemic may well have contributed to the negative findings presented in our paper. As debates around new medications post-pandemic gain momentum (Sarazin et al., 2024) there is a risk they may further divert attention from the precarious nature of dementia care and social support.

Learning for Future Crises

There are some key learning points from our findings, consistent with the wider evidence concerning the importance of valuing care and prioritising the social environment for people living with dementia, that could inform service responses to future crises:

(1) A proactive, personalised approach that recognises the value of the person living with dementia as a *person*. This may be as simple as services making check-in calls or offering walking appointments where home visits are not permitted.

(2) Delineating dementia groups as necessary care. The lack of in-person social and professional contact was the greatest concern identified by professionals, carers and people living with dementia in our combined analysis.
(3) Personalised care that prioritises the needs of the most marginalised, to prevent compounding existing inequalities. Our evidence supports the concern that people who were already disadvantaged by isolation and had poorer access to support (e.g. those living alone or who were digitally excluded), or had greater cognitive impairment to start with (limiting their ability to engage with changing models of delivery) were particularly marginalised during the pandemic.

Conclusions

This paper presents qualitative evidence from multiple perspectives on the impacts of changes to service delivery and the related social environment during the COVID-19 pandemic in England and Wales. Our findings show that the lack of in-person social and professional contact was of great concern to people living with dementia, family carers and health and social care professionals during the lockdowns. The pressure on carers to facilitate or directly provide social stimulation in the absence of previous opportunities for support and social contact had a detrimental impact on carers' own wellbeing.

In a 'post pandemic' society these findings remind us that personhood, maintained through social relationships, is at the heart of dementia care provision. Our conclusions centre on the importance of a person-centred approach that promotes the rights of the person in their social context and provides opportunities for continued engagement and citizenship. Person-centred care can be achieved in even the most challenging of circumstances and should be a core consideration of any planning for future disruptions to society, including valuing social wellbeing alongside medical need.

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Ethical Considerations

Ethical approval for PriDem was granted by NHS Research Ethics Committee Wales 3 (reference 18/WA/0349). Ethical approvals for the DETERMIND-WS4 and DETERMIND-C19 studies were obtained by the HRA Brighton and Sussex Research Ethics Committee [REC 19/LO/0528. IRAS 261263].

Consent to Participate

All participants in this study gave informed consent to be interviewed, either written or verbal (if the latter this was audio-recorded and witnessed by a researcher). All participants had capacity to give informed consent.

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Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Availability Statement

For information on PriDem data availability see https://research.ncl.ac.uk/PriDem/ For information on the availability of DETERMIND qualitative data used in this paper please contact the corresponding author kate.gridley@york.ac.uk

Disclaimer

The views and opinions expressed here are those of the authors and do not necessarily reflect those of UKRI, ESRC, NIHR or the Alzheimer's Society.

Note

1. https://www.england.nhs.uk/coronavirus/documents/information-about-the-end-of-the-shielding-programme-and-managing-the-closure-of-the-shielded-patient-list/#information

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Dr. Marie Poole is a senior qualitative researcher and NIHR Dementia Research Fellow at Newcastle University with a special interest in the experiences of people living with dementia, their carers and care professionals. Her research spans pre-diagnosis through to end of life care in a range of settings including the community, primary care, respite care, care homes and hospital settings. She supports approaches which recognise the rights, values, wishes and abilities of people living with dementia and is passionate about supporting underserved communities through novel service provision such as football clubs.

Professor Yvonne Birks is the national Director for the NIHR School for Social Care Research and leads research on services for older people and people living with dementia, especially those who self-fund their care. In 2023 she was awarded National Institute of Health and Care Senior Investigator status in social care research and led an NIHR Health and Care Services Delivery Research award supporting the development of research capacity and knowledge exchange in and with local authorities.

Dr. Ben Hicks is a Principal Research Fellow at the University of Nottingham and the DETERMIND Programme Co-ordinator. His research concerns supporting quality of life and social inclusion for people living with dementia through exploring the differing lived experiences of the condition and addressing the inequalities that may arise in the dementia care pathway. His PhD focussed on examining and supporting social inclusion in rural-dwelling older men with dementia through a community technological initiative tailored towards their multiple masculinities.

Dr. Josie Dixon is an Assistant Professorial Research Fellow in the Care Policy and Evaluation Centre, London School of Economics and Political Science. Her research focusses on ageing and care, particularly end-of-life care, dementia care, and social care for older people. In previous roles, Josie has directed Government and other nationally commissioned qualitative and mixed-method research projects and worked with local leaders to improve strategic planning and service provision.

Dr. Alison Wheatley is a social researcher with a background in the sociology of health and illness and a particular interest in health technologies. She worked as a qualitative researcher on the project 'Developing an intervention for fall-related injuries in dementia' (DIFRID) and has published previously on post-diagnostic dementia support during COVID-19, and on research into the outcomes valued by people living with dementia and their care partners.

Professor Louise Robinson is a GP and Regius Professor of Ageing at the Newcastle University Institute for Ageing. She was the first GP to be awarded a prestigious NIHR Professorship and holds the first UK Regius Professorship in Ageing. Louise leads a research programme focussed on improving quality of life and quality of care for older people, especially those with dementia. Louise was primary care lead for the Prime Minister's Dementia Challenge, is a member of the National Dementia Care Guidelines development group and was the PriDem Principal Investigator.

Professor Sube Banerjee is Pro Vice-Chancellor for the Faculty of Medicine and Health Sciences University of Nottingham and works as an old age psychiatrist. He is active in health system development for older adults and those with dementia and served as the UK Department of Health's senior professional advisor on dementia leading the development of its National Dementia Strategy. An active researcher, he has been awarded national and international awards for work in policy and research in dementia and is the DETERMIND Principal Investigator.