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EDITORIAL

THE COVID-19 PANDEMIC IN UK CARE HOMES – REVEALING THE CRACKS IN THE SYSTEM

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Introduction

There are around 420,000 residents living in UK care homes (1). The majority are over 85, have multiple health conditions, live with frailty and are nearing the end of their lives. Up to 80% of residents live with dementia (2). Care homes are not part of the National Health Service (NHS). Care home places are funded through a complex mix of self-funding, means-tested support from local authorities, and continuous healthcare funding from the NHS. They are run by independent organisations. A third of providers are large for-profit chains, the remainder comprising not-for-profit third-sector organisations, or small private companies with only a small number of homes (1). The level of government reimbursement for long-term care homes in the UK is low by international standards, an issue highlighted by multiple public commissions (3, 4) but which has gone unaddressed by successive UK governments.

Medical care to UK care homes is highly variable. In some areas, the NHS Care Home Vanguards have established dedicated General Practitioners with responsibility for each home and direct access to specialist multidisciplinary teams, with evidence that such approaches may minimise unnecessary admission to hospital (5). But often, care is based on residents' individual relationships with family doctors, with the result that access to medical care is variable and uncoordinated (6). As the COVID -19 pandemic started, arrangements for medical care in English care homes were in the early stages of being standardised as part of the NHS England Enhanced Health in Care Homes project (7).

There is a social dread surrounding care homes, perceived as places to avoid because of concerns about care quality and resistance to having to pay for social care when health care is free. Most of the coverage of care homes in mainstream media prior to COVID was negative, focussing on isolated scandalous cases of negligence or abuse, and rarely reporting on the exceptional work done by the sector daily. The workforce is not valued. There is no national accreditation for care home staff, opportunities for career progression are limited, staff are poorly paid and positions in care homes are often referred to as unskilled work (8).

It was clear from the experiences of Italy and Spain that the already compromised care home sector in the UK would struggle when faced with the COVID-19 pandemic. The pandemic has, though, been catastrophic for many care homes. In England and Wales, 29,393 excess deaths were reported for the care home sector between 28th December 2019 and 12th June 2020 (9). 19,394 deaths were directly attributable to COVID-19. As of 12th June, care home deaths caused by COVID-19 comprised 47% of all deaths attributable to COVID-19 in England and Wales.

The makings of this catastrophic death toll lie in the ways in which successive administrations have refused to plan proactively for care in care homes. These long-term deficiencies have manifested in important systematic failures during the pandemic.

The paucity of useful guidance for care homes

Up until the 2nd April, the only specific mention of care homes in government guidance on the COVID pandemic in England related to discharge from hospital (10). Care homes were asked to remain open to hospital discharges. This was coupled to removal of the usual funding assessments for placement in care homes, the net effect of which was to remove barriers and accelerate discharges from hospital. No specific guidance was given about requirements regarding COVID status of new admissions to care homes, quarantine or isolation measures, or the types of Personal Protective Equipment that staff should wear.

On 2nd April, care home-specific guidance was produced (11) which provided clarity on some aspects of care but remained silent or ambiguous on two important operational issues:

- The guidance stated that care homes could safely isolate new admissions and made passing reference to "cohorting" of COVID cases but provided no guidance about how to do so. Care homes vary widely in shape, size, and structure, and older buildings may not have been designed with infection control practices in mind. For these reasons specific guidance around cohorting was needed. To date it has remained incumbent upon third sector organisations, such as

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Bushproof (12), and professional organisations, such as the British Geriatrics Society (BGS) (13), to provide operational guidance on how cohorting or zoning based on infection-risk could work in practice.

- Swabs for COVID PCR tests were advised for "up to" the first five symptomatic residents of each home, with no clarity on what would happen for subsequent symptomatic residents. Tests only became available for all symptomatic residents on the 15th April (14), and it wasn't until 6th June that a blanket approach to testing all care home residents was introduced. Regular surveillance swabbing for staff and residents eventually commenced on 5th July (15).

The absence of data on care homes

There is no shortage of data about care home residents held by the NHS and social care or completed by care homes themselves. However it is not held in one place, is inaccessible to those who need it and, without that, the care home population is largely invisible to policy makers and commissioners (16). Early in the pandemic there was no reliable mechanism for collating data on infection rates in care homes. It wasn't until 28th April, that the government developed a mechanism for collating death certification data and presenting these alongside statistics for hospital deaths through the Office of National Statistics. Coupled to the lack of data from swab tests, this effectively neutered public health responses to COVID in care homes.

Historical lack of anticipatory care practices

Important challenges have faced care home teams during the pandemic. Given the high mortality associated with COVID in care home residents (17) and the limited treatments available, advance care planning discussions were appropriate and were a centrepiece of BGS guidance produced early in the pandemic (13). Yet they proved difficult to do in the context of COVID. The intention was widely misunderstood as clinicians wanting to block residents' access to treatment (18). This was compounded by the one thing that government guidance was clear on early in the pandemic, the need to stop families from visiting (11). Most general practitioners and community health teams adopted policies of staying away from care homes, except where attendance was essential. This led to difficult, and often inadequate, discussions with residents and relatives, at a time when many were upset by the abrupt cessation of visiting, by phone or videoconference.

Delirium was a presenting feature of COVID in up to 34% of residents (17). Coupled to the high prevalence of dementia in care homes, this meant that behavioural care plans were core to effective quarantine and isolation. Generating such plans in the context of COVID, where staff were thinly stretched, proved challenging. Care homes which had invested time in understanding the histories and behaviours of their residents, and in behavioural care planning, before the pandemic were much better placed to respond.

The failure to value and support care home staff

A national initiative, "clap for carers", where members of the public would take to the street and clap in appreciation of the sacrifices being made by those in health and social care, became established across the UK early in the pandemic. Originally, though, it was called "clap for the NHS". Extending this to involve care home and domiciliary care staff was an afterthought (19).

Staff form lasting bonds and close personal relationships with their residents and COVID-19 has been emotionally gruelling for care home staff. 56% of UK care homes included in the Vivaldi study (9) reported at least one case of COVID-19 in a resident and homes with outbreaks have experienced mortality rates of up to 26% (17).

The UK media has been filled with stories of care home staff going "the extra mile" for their residents including numerous examples of staff moving away from their families and into care homes to cover staffing shortages or to maximise infection control.

There is no doubt that the public estimation of care home staff has shifted during the pandemic. Yet they remain underpaid and under-supported by comparison with equivalently skilled NHS counterparts. Recent comments by the Prime Minister (20) that care homes did not follow guidance has provoked outrage from the sector at the misrepresentation and diminishment of what was achieved against the odds.

Discussion

By early July, England finally has a comprehensive policy for isolation and quarantine, diagnosis, surveillance and management of residents that reflects our understanding of the transmission and trajectory of COVID in care home residents. At best this suggests that our government has been slow. At worst, it suggests that they chose to prioritise hospitals and ignored the impact this would have on care homes who did not have the advice and resources they needed.

COVID has shown the cracks in our system and the centrality of care homes to a functional and functioning health and social care system. The failure to recognise this has resulted in the highest mortality rates in Europe. There is no doubt that stricter quarantine, widespread testing, better data, and more embedded anticipatory care practices could have resulted in better outcomes for residents and fewer deaths.

Gerontologists have written for years about the need to structure effective healthcare in care homes (21, 22), the importance of minimum datasets (16) and the need to better recognise and support care staff (8). We know how to do this. We can but hope that the mortality figures and the

unprecedentedly positive attention by the UK public and media on care homes will at last move our government to action.

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