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# Structural Discrimination and Abuse: COVID-19 and people in care homes in England and Wales

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- Purpose

The purpose of this paper is to explore the significant and high death toll of COVID-19 on care home residents and social care staff in England and Wales. These mortality figures, alongside differential treatment of residents and staff during the pandemic, are conceptualised as a form of structural abuse. Arguments are made for the inclusion of structural abuse as a separate category of elder abuse.

- Design/methodology/approach

This paper is predominantly conceptual but it also draws on available secondary data, such as mortality statistics, media reports, and developing research.

- Findings

The lack of appropriate personal protective equipment (PPE), paucity of guidance and high mortality rate amongst care home staff and residents during the pandemic is indicative of social discourses that, when underpinned by ageism, reflect structural elder abuse.

- Originality

Research concerning the effects and impact of COVID-19 are still in their early stages. However, the central element of originality in the paper concerns the linking of practices, policies and underlying social assumptions and structural, or societally ingrained, elder abuse.

- Research limitations/implications

The research is limited by its focus on a specific time period and its recency. It is also limited in not being based on primary empirical research but it remains exploratory and conceptual and provides a base for on-going research in this area.

- Social implications

If structural elder abuse were to be included in classifications it demands a rethink of social and health care services and the policies and practices associated with them and reinforces the government message that safeguarding is everyone's business.

## Introduction

The number of people in dying in care homes in England and Wales rose sharply throughout 2020 in line with a surge in COVID-19 infections. This paper argues that this rise illuminates an underlying lack of concern for older people in general and specifically for those living in care homes or with dementia. It betrays an attitude that devalues lives according to disease and age. The mortality data, policy and practice suggests that this lack of concern is built into societal mores and reflects what we term 'structural abuse' (Penhale and Parker, 2020), which we understand as an in-built, unquestioned devaluation of people through policy and practice based on certain characteristics. It is not something that people are necessarily aware of but, once exposed, is something that may appear to be logical and acceptable. We posit that the rise in care home deaths resulting from and associated with COVID-19 illustrates an underlying, yet prevailing, social maxim that the human worth of older people, especially those with dementia, is less than others in society and is responsible for structural elder abuse. Whilst it is recognised that structural abuse affects people of all ages and social groups, the focus in this paper concerns older people in care homes as this starkly demonstrates some of the impacts during a time of crisis. It indicates that attention needs to be paid to socio-political matters as they affect people and specifically that older people's rights, especially in care homes, merit specific treatment (United Nations, 2020).

## Elder abuse and structural abuse

Elder abuse is acknowledged as a global phenomenon, yet its definition remains as contested and as elusive as ever, even more so within care homes (Penhale, 2008; Penhale and Parker, 2020). Whilst elder abuse has a long history its relatively short recognition in academic and professional circles perhaps exposes some of the ageist discourses underlying policy development (Bennett *et al*., 1997; Penhale and Parker, 2008). The WHO (2020) definition of elder abuse is commonly referred to:

> 'Elder abuse can be defined as "a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person". Elder abuse can take various forms such as financial, physical, psychological and sexual. It can also be the result of intentional or unintentional neglect.'

This definition was taken from that composed by Action on Elder Abuse, now Hourglass, who developed this in 1993. This definition appears, at first glance, to focus predominantly on individuals experiencing or perpetrating abuse, whereas research using such a definition tends to focus on statistical analyses, prevalence and incidence rates (Garnham and Bryant, 2017; Penhale and Parker, 2020). Whilst this is important in respect of interpersonal and individual care needs, such an approach could allow systemic structural abuse to go unchecked and unnoticed through ageist policies, practices and perceptions and, therefore, to allow government to escape responsibility for ensuring the adequate and appropriate treatment of those living and working in care homes.

The WHO definition does not, in fact, preclude structural causes. Policies and practices that affect older people may cause harm or distress, are singular or repeated, or may not feature in the panoply of a government's social measures. Without getting into a philosophical discourse on the vexed question of the social contract, each citizen's relationship with the government has been built on trust involving entitlements and responsibilities. Where governments fail to provide appropriate services or mistreat their citizens, trust is broken and harm and distress are possible. In this paper, we are taking the view that increased deaths in care homes in England and Wales during the COVID-19 pandemic represents structural elder abuse. We also contend that an overt definitional category of structural elder abuse is long overdue.

It was in 1993, in the UK, that elder abuse was recognised, by government, as a social problem to tackle (Department of Health, 1993). Despite a lack of consensus on definitions, there is general agreement on the typology of abuse including, physical, sexual, financial, psychological/emotional abuse and neglect (sometimes including self-neglect). These concern intra- and interpersonal actions or inactions, although they do not, of course, necessarily exclude structurally embedded abuse through policies and general assumptions of behaviour. For instance, UK family policy focuses on individuals and their responsibilities, with childcare policies assuming the (usually female) family and grandparental care of children (Skeggs, 1997; Pascall, 2012).

Institutional abuse has been considered as a specific focus of attention, which illustrates the importance of organisational contexts (Stanley *et al*., 1999; Kayser-Jones, 2002; Parker, 2001; Jönsson, 2016; Penhale and Parker, 2020). Also, in earlier guidance in England and Wales, discriminatory abuse was added to the typology (DoH, 2000; WAG, 2000), which seemed to indicate a move to conceptualise abuse as a multi-systemic social problem at structural, organisational as well as personal levels. However, the consolidating aspects of the Care Act 2014, whilst expanding aspects of violence and harm for at-risk people, has shifted this understanding back to a more interpersonal perspective. This is, perhaps, a retrograde step; understanding abuse through a systemic perspective, and acknowledging it as a socially constructed entity, allows us to tackle elder abuse at a range of levels. Treating it as an individual matter, on the other hand, allows organisations and governments to distance themselves from responsibility. This, in turn, reinforces the unspoken, tacit view that older people's lives are less valuable than those of younger people. The conditions for structural oppression are built into these accepted, dominant narratives (McCreadie, 2006).

Structural oppressions are, amongst other intersecting characteristics, gendered, racialised, socio-economic, health-focused and age-related and are rooted within the everyday workings of social systems (Crenshaw, 1989; Parker and Ashencaen Crabtree, 2018; McVey *et al*., 2020). Dominant and unspoken assumptions influence the ways in which care policies are developed, delivered, and the eligibility criteria

are used to apportion care. However, the affects are wider still and there is an associative element in which those working in care, with older people, in care homes and people with dementia are also viewed as subordinate and less worthy and, therefore, likely to receive less resource and support (Parker, 2007; 2020). This is substantiated in respect of the isolation experienced by care home residents and lack of attention to human rights for dignity and the rights to life (Argyle *et al*., 2017; United Nations, 2020)

We argue that structural elder abuse has characterised care home residents and staff throughout the COVID-19 pandemic.

## Methods

This paper uses the Office of National Statistics mortality data for 2020 to explicate the impact of COVID-19 and data from previous years to detail the increase in deaths in care homes in England and Wales over time. Public Health England data are also used. Additional data are provided by the Vivaldi Study (2020), commissioned by the Department for Health and Social Care (DHSC), and from the Health Foundation. Media, official reports and existing literature are used to explore failings of government in terms of support and guidance for care homes, in ensuring an adequate supply of personal protective equipment (PPE), and testing and tracing for care home staff throughout the pandemic and the two major spikes in 2020.

Limitations resulting from the methods include the secondary nature of the research and early collection of data, the on-going and ever-changing situation and recency of the pandemic and specific focus on one section of society. Whilst a more in-depth, ethnographic study would be likely to provide richer and more nuanced data concerning the function and impact of structural issues, the use of existing data provides a beginning insight from which further research can be developed.

## Findings

### *Care home mortality data*

In non-COVID times, older residents in care homes experienced higher mortality (Shah *et al.*, 2013). However, Office for National Statistics (ONS) figures show a decreasing number of deaths in England and Wales (ONS, 2020a). The provisional

Office for National Statistics (ONS) report concerning care home deaths during the COVID-19 pandemic, published in July 2020, examined the first wave of the pandemic between 2 March and 12 June 2020 showing a clear rise in mortality figures (ONS, 2020b). Overall, there were 66,112 deaths in care homes in England and Wales of which 29.3% (19,394) involved COVID-19, with England showing significantly higher deaths. The majority of deaths of care home residents occurred within care homes (74.9%; 14,519), with 24.8% (4,810) happening in hospital. During the reporting period COVID-19 was the leading cause of death amongst male care home residents and the second leading cause for women, after dementia. Indeed, dementia was the predominant pre-existing condition in COVID deaths. Table 1 shows the leading causes of death in care homes over the period.

*Add table 1 here*

The Vivaldi study undertook telephone interviews with managers from 5,126 care homes in England with responsibility for offering care older people and those with dementia between 26 May and 20 June 2020. Managers were asked for information on residents and staff who tested positive for coronavirus since the beginning of the pandemic. This sample represented 56% of the 9,081 care homes in this category. Data collected indicated that there was at least one confirmed case of COVID-19 (resident or staff) in 56% of responding care homes, which led to estimates that 20% of residents and 7% of staff had tested positive since March 2020. Where there were higher rates of resident infection, there also seemed a prevalence in staff, but where sick pay was paid to staff there seemed to be lower levels of staff infection. Where there were higher levels of staff infection there was also, albeit lower, a prevalence of infection amongst residents. Estimates in the Vivaldi study were based on those tested and did not include those who may have had COVID-19 but were not tested. It is suggested this may mean rates are underestimates. Table 2 shows the proportions of infections in care homes.

*Add Table 2 here*

The impact of COVID-19 on care home residents and staff was also detailed by the Health Foundation (2020), who identified central weaknesses in the social care system.

While deaths from coronavirus were declining in the first wave at the week ending 17 April, the spread was still rising in care homes and even exceeded hospital deaths from COVID-19 by the week ending 1 May 2020, possibly also reflecting the discharge of patients from hospital to care homes when COVID-positive. The Health Foundation also recognised the effects on social care staff, noting their death rate was three times higher than that of the general population.

Whilst care home residents may have a greater number of underlying health conditions and it may be expected that death rates would be higher than community ones, the fact that deaths exceeded those in hospital, that hospital patients were discharged to care homes when COVID-positive and the increased numbers of deaths amonst care home staff indicates a COVID effect. These data reinforced the call for a charter of human rights for older people with the Secretary General of the United Nations' (2020) drawing attention to increased care home deaths, denial of health care and associated abuse and neglect of care home residents.

***Lack of PPE, guidance, testing and tracing for care home staff***

In late March 2020, Iacobucci noted that evidence to a Health and Social Care Select Committee meeting from the Local Government Association, Association of Directors of Adult Social Services and Care England described a lack of personnel, funding and PPE was setting the conditions for increasing infections and that testing would be a priority for care home staff to curb the rate of infection.

As the scale of the pandemic grew in England and Wales during the first wave, reports concerning the paucity of PPE abounded in the professional press and confirmed by practitioners and home managers. In May, Jones-Barry (2020) reported that the National Care Forum and the UK Homecare Association were experiencing a lack of availability and rising costs for PPE, alongside a lack of testing for staff and residents in care homes. It seemed that the NHS was procuring all available supplies of PPE. Nursing media and professional bodies also provided experiential reports which concurred (Ford, 2020; RCN, 2020), as did print media of various political leanings (Savage, 2020; Middleton and Gordon, 2020). The Royal College of Nursing (RCN) identified the many nursing staff working in care homes without adequate PPE and sanitizer and called for this to be redressed. This was also highlighted by

mainstream TV media (ITV, 2020). Interestingly, it took a campaign by a major Trade Union for social care workers to highlight that VAT was being charged on PPE and that this should be removed (UNISON, 2020).

In a pre-print study, Brainard *et al*. (2020) completed on a secondary analysis of a dataset relating to care homes in Norfolk. The study concluded that infection increases were strongly related to lack of facemasks and eye protection amongst care home staff. However, publicising the lack of PPE was thought by one provider to have created a mind-set amongst the general public that care homes were failing residents and were 'no go' zones (Learner, 2020). The achievements of staff in protecting residents and the dedicated, positive work undertaken was forgotten, an unintended consequence of unquestioned actions (see Merton, 1936). This seems to support the hypothesis that social and political discourses have perpetrated the maltreatment of those in care homes and, by association, social care staff.

The paucity of supplies of PPE was replicated in the United States (US) (McGarry *et al*. 2020; Seegert, 2020). Residents receiving Medicaid, the poor and clinically vulnerable, and staff serving them, were less likely to receive support, adequate levels of PPE and had higher mortality rates. This is perhaps to be expected. Whilst the care home and social care contexts are different between the US and England and Wales, the same neoliberal market driven economy that privileges those who are economically active and viable obtains in both settings.

The Department of Health and Social Care winter plan to curb infections added £546 million to the budgets of care home independent of local authorities to help with staffing and promised free PPE until March (Department of Health and Social Care, 2020). However, this is allocated at an 80/20 per cent split with the final 20% being discretionary. Also, care home leaders are still worried that this, remedial action, would not be sufficient in tackling a resurgence of the virus over winter (Barker, 2020).

Despite these measures being welcome. They do seem redolent of 'catch-up' behaviour responding to public pressure and reflect the paucity of appropriate treatment and resourcing previously.

On 2 November 2020, as a second wave of coronavirus infections was rising in England and Wales, Public Health England (2020) published extensive and revised guidance on the use of public protective equipment (PPE) for care home staff. Guidance had originally been published in April but there remained claims of a lack of appropriate and clear advice.

That care homes represented a priority for coronavirus testing was recognised early in the pandemic (Iacobucci, 2020; Jones-Barry, 2020), but also rising confusion and the passing of responsibility for testing between Public Health England, the Care Quality Commission and the Department of Health and Social Care was also reported (Booth, 2020). As potential vaccines come closer, it must be acknowledged that social care staff and care home residents, as people deemed vulnerable to the effects of COVID-19, are considered by the independent advisory Joint Council on Vaccination and Immunisation (JCVI) to represent a priority group for the vaccine because of the clear research concerning care home susceptibility to infection and high numbers of deaths (JCVI, 2020). Whether this advice is accepted remains to be seen but it seems to highlight a response to a public outcry that recognises systemic maltreatment.

## Discussion

We have considered mortality data and lack of resources to illustrate structural elder abuse during the pandemic. These are observable phenomena that betray the existence of underlying discriminatory attitudes towards older people in care homes and people living with dementia that are played out at governmental and service provider levels. Thus, they provide evidence of structural elder abuse.

### *Ageism in society*

Since Bytheway's (1995) erudite summary of ageism in the 1990s the systemic nature of discrimination has been increasingly recognised. Social gerontology has exposed the social constructions of chronological age and the ways in which older people, especially those with life-limiting or chronic health conditions, have been problematized and marginalised. Brownwell and Powell (2013) identified this in the workplace and Phelan (2008) also recognised this association in nursing practice. Biggs and Haapala (2013) made the important association between social ageism and

elder abuse and posited that the relationship between the individual and the state represents an important site for the study of elder abuse.

In the pandemic we have both ageism, in which older people in care homes are categorised and treated negatively in relation to others in society, and 'ageism by association' (Burke and Parker, 2007) in respect of social care staff with disproportionate infections and a three times higher death rate to the general population, lack of PPE and appropriate guidance. This represents ingrained societal abuse of older people who are valued differently and treated as less eligible and less important than younger people in society. We may posit that this stems from an innate fear of people towards the end of their lives resulting from the compartmentalised ways in which we live now in the UK. It may also result from the economic imperative associated with human worth.

***Structural discourses***

Sociological approaches to elder abuse have long recognized the involvement of structural factors in creating and reproducing differential treatment (Phillipson, 1997). As elder abuse became officially recognized in France, Scodellaro (2006) highlighted the importance of social relation and appropriate environmental contexts to prevent physical or psychological suffering. She focused on the widespread causes of abuse that could be personal contextual and structural (see also Dow, 2012).

The conditions that permit elder abuse to happen are recognized to be socially and politically constructed (McCreadie, 2006), and broad-based (Lindenberg *et al*., 2013). Lonbay (2018) recognized that structural barriers existed in the UK to older people participating in the safeguarding process. It has even been suggested that research has been characterized by the marginalisation of the individual and replaced by a more palatable statistical approach, what Garnham and Bryant (2017) call 'epistemological erasure'.

Clear recognition of structural abuse was identified by Bennett (2014) when discussing legal charges of elder abuse being leveled against San Francisco's approach to housing. Also, Kabelenga's (2014) work in Zambia noted that older people were being politically abused and called for an extension to the definition of

elder abuse to incorporate such, alongside adding spiritual abuse. This echoes Anand *et al*.'s (2013) call for the inclusion of indigenous perspectives when defining elder abuse so as to guard against monolithic interpretations. Indeed, unquestioningly accepting normative definitions and approach could be construed as abusive in itself.

Whilst dementia is not exclusively a disease of older age, its incidence and prevalence rise with age. In earlier research, we suggested that dementia represented a *zeitgeist* in global policy, research, funding and practice and, as such, dementia care was precarious and at risk of displacement by other more pressing or 'worthy' social issues (Parker *et al*., 2020). The COVID-19 pandemic showed this was the case by initially displacing all former health imperatives to tackle the crisis. However, the rise in deaths of people living with dementia in care homes represents an example of inbuilt discrimination as well as a shift in *zeitgeist*.

The COVID-19 pandemic attracts further consideration of structural abuse (Human Rights Watch, 2020). Of course the risks of working in any care setting in a time of pandemic are likely to be higher than that for the general population. However, the risks posed to social care residents seemed to outweigh those in hospitals and in the community. Risks posed to social care staff also rose accordingly. This suggests that there may be structural reasons that less attention, resource and care is given to this sector because those within it, as either residents or staff, are deemed less worthy or valuable. This trope, concerning the 'deserving' and 'undeserving', has existed for a long time and characterises an increasingly harsh rhetoric against some of the most vulnerable in society (O'Hara, 2020). Older people and people living with dementia have been consigned to the less eligible category in a systemic way during the pandemic indicating structural elder abuse. Care staff have also experienced these structural disadvantages by association (Parker, 2007); something which is reflected in the November 2020 spending review in which alongside other public sector workers, except those in the NHS, were to experience a pay freeze.

The potential breaches of the European Convention on Human Rights and articles 2, 3, 8, 14 of the Human Rights Act 1998 have led to permission being granted for a judicial review of care homes policies (Scott, 2020). The claimants argue there has been a failure to implement an adequate regulatory, and operational system to protect

vulnerable people wellbeing, health and lives, which denies the right to family life by the virtual incarceration of older people in care homes during the pandemic. The application also claims that this results in age discrimination that breaches the Equality Act 2010 and public law. This further suggests a deep-rooted structural discrimination towards and abuse of older people in care homes.

**Implications for practice and recommendations**

There are some things that government could do to immediately counteract some of the structural disadvantages experienced by people who live or work in care homes. Firstly, it is important to ensure that COVID-positive patients who have been hospitalised are not discharged when still infectious. Vaccination of care workers alongside residents should continue to be prioritised and a commitment should be made to supplying adequate PPE, up-to-date and effective guidance and training. COVID-safe ways of ensuring residents' families and loved are able to visit and support residents in meaningful ways should be developed.

Adding structural abuse to the definition of elder abuse would represent an important stride forward in protecting resident and care home staff rights. Whilst most of the criminal acts associated with currently accepted types of abuse can be prosecuted under English and UK law, addressing structural abuse is more equivocal. It may be that it breaches human rights legislation, and some policies may run counter to the intentions of the Care Act 2014 in England or the Social Services and Well-Being Act 2015 in Wales; however, recourse to the law is less likely as a remedy, especially for practitioners. Adding structural abuse to the definition would ensure that governments, policy-makers and social and health care providers were also held to account and the blame attached to individual perpetrators was not allowed to deflect attention from societal wrongs. Abusive individuals cannot be made the scapegoat to carry the blame for abusive policies whatever their wrongful actions and omissions as individuals. Including structural abuse as a category in elder abuse also allows for societal reflection on what kind of people we want to be, to expose our thinking to critical analysis and to seek equitable treatment of all members of society. It, therefore, reflects an ethic that values the worth of every human being because they are a human being and without recourse to other evaluations.

Adding such a classification could put those working in health and social care services in a difficult position vis-à-vis their employers, whose policies, procedures and practices may be under question. For nurses and social workers, however, it is imperative to maintaining professional ethical integrity. For health and social care workers, the reports into structural aspects of ill-health and COVID-19's greater impact on those from socio-economically deprived areas also demands attention (see Marmot Report, 2010; Institute of Health Equity, 2020). The Black Report (DHSS, 1980) drew attention to health inequalities, which were still prevalent during the COVID crisis (O'Dowd, 2020). So, its addition will strengthen codes of practice and ethics that require advocating on behalf of those put at risk, whatever the source of that risk.

**Conclusion**

This paper has argued for the development of our understanding of adult abuse, focusing on older people, by adding structural abuse. The experience of care home residents and staff during the pandemic has been one of being marginalised through lack of PPE and guidance, and being ignored when there have been rising death tolls among both groups, not preparing adequately for family visits and interaction, and blatant disregard for life and rights through the discharge of COVID-positive patients back to their care homes.

Overall, it is important that we understand elder abuse and the safeguarding, role as fluid rather than monolithic, an iterative process that seeks the best possible ways of safeguarding people from harm at all levels - whether from the self, others, services and organisations or the state. This is particularly important when we consider changing ways in which people are viewed according to living context and environment, especially during a time of pandemic, and therefore for people living and working in care homes.

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**Table 1: Percentage of deaths of care home residents and non-care home residents for the five leading causes of death from 2 March to 12 June 2020, registered up to 20 June 2020, in England and Wales**

| **Male** | | **Female** | |
|---|---|---|---|
| Care home residents: | | Care home residents: | |
| COVID-19 | 33.5% | Dementia and Alzheimer disease | 33.8% |
| Dementia and Alzheimer disease | 24.7% | COVID-19 | 26.6% |
| Cerebrovascular diseases | 4.4% | Symptoms signs and ill-defined conditions | 7.0% |
| Ischaemic heart diseases | 4.0% | Cerebrovascular diseases | 5.0% |
| Symptoms signs and ill-defined conditions | 3.4% | Ischaemic heart diseases | 3.1% |
| Non-care home residents: | | Non-care home residents: | |
| COVID-19 | 26.3% | COVID-19 | 20.1% |
| Ischaemic heart diseases | 13.0% | Ischaemic heart diseases | 8.0% |
| Malignant neoplasm of trachea bronchus and lung | 5.5% | Dementia and Alzheimer disease | 6.2% |
| Chronic lower respiratory diseases | 5.3% | Malignant neoplasm of trachea bronchus and lung | 6.1% |
| Cerebrovascular diseases | 4.1% | Chronic lower respiratory diseases | 6.0% |

Source: Office for National Statistics – Deaths involving COVID-19 in the care sector

**Table 2: Estimated proportion of coronavirus cases reported by care homes, with 95% confidence intervals**

| | Estimated proportion (number) | 95% confidence interval | |
|---|---|---|---|
| | | Lower | Upper |
| Proportion of care homes with at least one case of coronavirus (staff or resident) | 55.6% | 54.8% | 56.4% |
| Proportion of care home residents testing positive for COIVD-19, in care homes with at least one case of coronavirus | 19.9% | 18.5% | 21.3% |
| Proportion of care home residents testing positive for COVID-19 across all 9,081 care homes | 10.7% | 10.1% | 11.3% |
| Proportion of care home staff testing positive for COIVD-19, in care homes with at least one case of coronavirus | 6.9% | 5.9% | 7.9% |
| Proportion of care home staff testing positive for COVID-19 across all 9,081 care homes | 4.0% | 3.6% | 4.4% |

Source: Vivaldi Study (2020)/Office for National Statistics