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The covid-19 pandemic and care homes for older people in Europe - deaths, damage and violations of human rights

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ABSTRACT

Throughout Europe the most damaging consequences of the coronavirus have fallen disproportionately on older people who live in care homes. This study involves the analysis of secondary data sources relating to deaths, and related harms, in European care homes from seven countries between March and December 2020. The findings are reviewed using the framework of the European Convention on Human Rights to identify examples of human rights violations - namely the right to life, liberty and security, respect for private and family life, and prohibition of torture, and general prohibition of discrimination. A significant contributing factor to the scale and nature of deaths and harms is the abject disregard of older people's human rights. Based on the findings, the authors, a group of social work academics, call for an urgent re-examination of the role of social work in relationship to care homes and the importance of re-engaging with human rights issues for care home residents.

KEYWORDS

Older people; covid-19; care homes; human rights; social work

Introduction

The World Health Organisation (WHO) estimates that older people living in care homes represent 50% of all Covid-19 related deaths in Europe; it describes the situation as an 'unimaginable tragedy' (WHO, 2020). Although the final death toll will not be known for some time, as of June 30th, 2020, 80,000 excess deaths have been linked to Covid-19 in European care homes (Comas-Herrera et al., 2020). In this paper the authors expose the deaths and harms experienced by older people living in care homes in seven European countries during the first 10 months of the pandemic using the European Convention on Human Rights lens.

The authors are members of the European Network for Gerontological Social Work, a special interest group aligned to the European Association for Social Work Research (https://www.eswra.org/about.php).

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Care homes are 'institutions and living arrangements where care and accommodation are provided jointly to a group of people residing in the same premises or sharing common living areas' (European Agency for Safety and Health at Work, 2017, p. 3). In most European countries care homes tend to be regarded as the place of 'last resort' and are situated geographically and metaphorically 'off the public radar'. Most care home residents are aged 85 years or over, have complex co-morbid conditions and need help with activities of daily living. Dementia is estimated to affect four fifths of residents (Dening & Milne, 2020). Over the last twenty years the care home sector has become increasingly privatised, fragmented, atomised and outside the purview of policy makers and the public sector, including social workers (Dening & Milne, 2020). This is important to note as several of the infrastructural challenges facing care homes during the pandemic relate to the nature of the sector: how care homes are provided and funded and who is 'responsible' for the funding and management of responses to the crisis (Milne, 2020). The shift 'towards the private' is especially relevant to care services for older people and is part of the jigsaw of issues that compromise service users' human rights (Milne, 2020a).

Social Work and Care Homes

In most European countries admission to a care home is based on a formal assessment; often involving a social worker who may be part of a specialist aged care hospital or community care team (Tanner et al., 2015). In some jurisdictions the local state has a specific, sometimes mandatory, duty to investigate instances of abuse or neglect including those arising in care homes; this investigation is often conducted by a social worker. Very few European care homes directly employ social workers to provide professional services.

In part, the limited involvement of social workers with care homes reflects a drawing back of the welfare state's responsibilities across Europe; generally only those older people with very high levels of need gain access to social work support. It also reflects the privatised and fragmented nature of the care home sector noted above. The fact that care homes are regarded as centres of 'treatment' as opposed to a 'home', tends to reduce resident's access to community and professional services, including social work and legal advocacy (Cook et al., 2015).

Care Homes and Covid-19: The European Convention on Human Rights

While advanced age, and its associated health-related comorbidities, is linked to increased mortality risk from Covid-19 this, of itself, does not explain the high rate of death and serious harms experienced by care home residents. The authors of this paper argue that (many) of these deaths and harms were preventable and were a consequence of the neglect of residents' human rights. This

Table 1. Five Articles of the European Convention of Human Rights.

European Convention of Human Rights 1950
Section 1. Article 2 Right to Life Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.
Section 1 Article 3 Prohibition of torture No one shall be subjected to torture or to inhuman or degrading treatment or punishment.
Section 1 Article 5 Right to liberty and security Everyone has the right to liberty and security of person. No one shall be deprived of his liberty.
Section 1 Article 8 Right to respect for private and family life Everyone has the right to respect for his private and family life, his home and his correspondence.
Section 1 Article 14 General prohibition of discrimination The enjoyment of any right set forth by law shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

Source: https://www.echr.coe.int/Documents/Convention_ENG.pdf

argument is illustrated through the lens of five Articles (see Table 1) of the European Convention for the Protection of Human Rights and Fundamental Freedoms (1950).

The European Convention on Human Rights - as it is commonly referred to - is the key instrument giving legal effect to rights, as stated in the Universal Declaration of Human Rights. The Convention is a shared framework which recognises that all European citizens have human rights, including care home residents (GAROP, 2010).

Review of Evidence

A review of evidence relating to violations of human rights of care homes residents and their families during the pandemic was conducted by the authors, between March and December 2020. Material from secondary data sources were collected from seven different European countries. These countries represent a spread of geographical areas (northern, middle, southern) and both higher (the UK, Sweden, Spain, Ireland, Italy) and lower (Finland, Estonia) Covid-19 infection rates. A range of materials were analysed, including peer reviewed articles, publicly available 'official' documents (e.g. government reports), and written and online media (e.g. newspaper reports, articles, blogs). Media sources were included as they captured - in real time - the developing care home crisis; reviewing material from a range of diverse sources is a legitimate and effective way to collect evidence in relationship to an emerging social phenomenon (Aron et al., 2020; Houston et al., 2015). Although some media reports could be considered 'subjective', the authors were careful to select sources that referenced actual events or were commentaries on data that could be independently verified. Two or more case examples were selected for discussion under each Article in relation to violations or infringements. Some of the evidence falls under more than one Article of Rights; where this is the case it is noted.

Article 2 - right to life

Care homes are entrusted with protecting residents' right to life. Table 2 - Older People's Deaths in Care Homes - during the first 4 months of the pandemic, shows the number of care home residents who died in five of our sample countries and the proportion of the total number of all Covid-19 deaths this figure represents (Aron et al., 2020). As can be seen the proportional figures range from 41% in the UK to 68% in Spain (Comas-Herrera et al., 2020). Unfortunately, we have no data for Italy or Estonia.

Other data relating to the nature of care home deaths is also important. In Spain more than half of the 1600 care home deaths in the first four weeks of March were due to Covid-19 (Dombey, 2020). During the same period, in one home in Madrid, over a sixth of the residents (n=25) died of the virus (Dombey, 2020). Between March and June, Spain experienced 20,649 deaths of care home residents; of these at least 18,811 were 'excess deaths' i.e. deaths over and above what would be expected for this period (Williamson, 2020). Similar trends were reported in the UK. By the end of June, the number of excess deaths of care home residents was estimated to be 26,745. In terms of spread,

Table 2. Older People's Deaths in Care Homes between March-June 2020.

Country	Number of deaths in care homes: March-August 20 (total number of older people in care homes in brackets)	Number of care home deaths as a percentage of the overall number of deaths
Finland	147 (50,298)	45%
Ireland	1,500 (16,007)	63%
Spain	20,649* (333,920)	68%
Sweden	2,714 (82,217)	47%
United Kingdom (& Northern Ireland)	35,500 (477,100)	41%

Key Source: Comas-Herrera et al. (2020) International Long-Term Care Policy Network.

the virus was reported in at least two fifths of care homes in England and three fifths in Scotland (Comas-Herrera et al., 2020).

There are several reasons for the large number of care home deaths. 'Failure to protect life' takes several forms. The UK's strategy of prioritising the protection of acute National Health Service (NHS) services at the expense of out of hospital 'at risk' populations was a key cause of excess deaths. At least 25,000 people were discharged from hospitals into care homes to free up beds between March and June 2020 (Iacobucci, 2020). This large group of patients were not routinely tested for Covid-19. In many cases the virus was brought into care homes where it quickly spread creating, what scientists call, 'fatal cluster effects' (Heymann & Shindo, 2020). Nursing Homes Ireland claims that 'hundreds of residents' were discharged from hospitals to nursing homes without being tested in a concerted push to 'purge older people from acute care beds' (Conneely, 2020). In Italy the deaths of care home residents from Covid-19 has been called the 'silent massacre' (Privitera, 2020).

The UK's Department of Health and Social Care (DHSC) was also slow to advise against visits to care homes from relatives, another obvious route of infection transmission (see Article 8 below). Agency staff - who often work across several care homes and who were relied on during the pandemic to provide cover for permanent staff who were ill or shielding - would also have been a key source of transmission (Milne, 2020). Even regular members of staff may have been carriers; this was certainly the case in Italy and is likely to have been the case in other European countries too (Privitera, 2020).

In Sweden, due to care homes not being treated as 'health care facilities', many residents with Covid-19 failed to be given access to life-saving treatments such as oxygen and intravenous fluids, but were instead offered palliative care (Hansson & Fröding, 2020). In many homes this took the form of a 'palliative cocktail'; this was often prescribed over the phone and included morphine and midazolam, which are respiratory inhibiting drugs. A well know geriatrician told a Swedish newspaper that in his opinion this practice amounted to 'active euthanasia' (Smith, 2020). This 'default practice' was influenced by a combination of official guidance from the National Board of Health and Welfare and a drive to keep hospital ICUs from being overwhelmed by older patients with a low chance of survival.

Health service-related deficiencies also contributed to the premature deaths of care home residents from non Covid-19 related health problems. It has been estimated that just under half the excess care home deaths in the UK were from 'other causes', including General Practitioners not being able to do visits and care homes being discouraged - or sometimes unable - to send residents to hospital for treatment for non-virus related health conditions (Alzheimer's Society, 2020; O'Dowd, 2020).

Shockingly, it has also been reported that some General Practitioners in the UK were asked to 'pressure care home residents into signing 'do not attempt resuscitation orders'' (DNAR) if they became ill with Covid-19 (Age UK, 2020). The Care Quality Commission (CQC) - which inspects the quality of care homes in England and Wales - also uncovered evidence that DNAR orders were issued for whole groups of residents without consent having been sought from either the resident themselves or their family (Amnesty International, 2020).

Lack of access to testing and personal protective equipment (PPE) was a key driver of the virus spreading rapidly. Incorrect assumptions about the non-transferability of the virus and lack of understanding about care home environments may have contributed to the high death toll in Sweden (Pierre, 2020). In Estonia, care homes were the last care service to receive PPE, and staff struggled to access professional advice on how to manage the virus, including how to reduce risk of death (Dominelli et al., 2020). In the UK, in mid-May, Age UK (a large older people's Charity) reported that 'many care homes are struggling to access testing' and 'a supply chain to tackle PPE shortages is weeks away' (Carter, 2020). One of the main reasons for this failure was confusion about which agency was responsible for overseeing and managing provision of PPE and testing to care homes. Public Health England (PHE), the CQC and the DHSC gave homes contradictory messages. Care homes report being told, in the same day, that it is CQC's responsibility and then subsequently

that its PHE's to provide them with PPE (Carter, 2020; Harwood, 2020). An 'Action Plan for Care Homes', which included commitment to providing PPE and testing, was not put in place by the DHSC until April 15th, 6 weeks after the government's national 'coronavirus action plan' which made no mention of care homes (Milne, 2020). In Italy, no tests were provided for care home workers for many weeks after the start of the pandemic; nor were they given proper PPE (Privitera, 2020). Many homes did not have sufficient physical capacity to offer effective isolation care for residents with the virus. According to a statement from the Italian Society of Gerontology and Geriatrics, Italy's 7,000 care homes were 'neither equipped nor had trained personnel' to deal with the virus; they became 'biological bombs of contagion' (Borghese & Braithwaite, 2020).

A key barrier to understanding the extent and causes of care home deaths, and thus develop protective responses, was lack of data. In several countries, including Finland and the UK, care home deaths were not included in official figures relating to Covid-19 deaths for some weeks into the pandemic. In Italy no national figures exist. Even when data is captured, it is collected in different ways and by different bodies in each country. A recent report by the European Centre for Disease Prevention and Control observed that, ' … under-ascertainment and under-reporting of Covid-19 cases in long term care facilities is a common feature across Europe' (p55). This significantly undermines timely reporting, makes meaningful analysis difficult and significantly impairs the capacity of care homes, wider care systems and policy makers to learn lessons from the pandemic (Hanratty et al., 2020).

Article 3: prohibition of torture

One of the most serious transgressions of human rights during the pandemic was the number of older residents who died alone in inhuman or degrading conditions. Unverified results suggest that a third of excess deaths in UK care homes were a result of 'being left alone without adequate food, water' or access to pain relief (Comas-Herrera et al., 2020). In Spain, there were reports that care home residents were deliberately left 'unattended' if they tested positively for Covid-19 (Rada, 2020). 83 residents in care homes in northern Italy reportedly went without food for two days because staff had to go into quarantine (Williamson, 2020). Italian authorities are investigating a string of violations. One example is a criminal case being brought by staff and relatives against a Milan care home for multiple manslaughter; they say that management palpably 'failed to protect residents and workers' and caused a great deal of harm (Wedeman & Ruotolo, 2020).

For people living with dementia who display behaviour problems - such as wandering, agitation or aggression - increased use of antipsychotics and hypnotics has been reported in the UK (Howard et al., 2020). Increased use of sedatives has also been reported, to ensure resident compliance with safety measures such as hand washing and social distancing (Valayudhan et al., 2020).

Another disturbing example of inhuman and degrading treatment relates to end-of-life care. Evidence from Ireland indicates that residents' wishes were either not sought or disregarded entirely (Brennan et al., 2020). As a result of relatives being excluded from visiting care homes, many residents died alone causing unimaginable levels of pain and distress to residents and relatives (McGarry et al., 2020). With extremely low staff/resident ratios during the early phases of the pandemic - due to staff shielding and/or being ill - staff were often not available to offer comfort or reassurance either (Wakam et al., 2020). The fact that some residents were kept isolated for safety reasons i.e. they may have had the virus and/or been recently discharged from hospital, compounded the problem. In Spain, the army found 'many dead bodies stored in care home mortuaries', awaiting transfer to funeral services (Mallet et al., 2020).

Article 5: right to liberty and security

During the pandemic care home residents' have experienced a range of violations to both their liberty and security (Brennan et al., 2020). Their rights were breached by jeopardising protection from possible carriers, or conversely, restricting liberty of movement. Neglectful or overly extreme responses to infection control in care homes has had detrimental consequences. In the UK, a

leading barrister suggests that one of the most profound examples of failure to uphold the right to liberty relates to care home residents who are the subject of Deprivation of Liberty Safeguards (DoLS) (Lewis, 2020); DoLS ensures people who cannot consent to their care arrangements in a care home or hospital are protected if those arrangements deprive them of their liberty. In the pandemic it is challenging to argue that living in a care home is preventing harm; in some instances, residents are being placed directly in the path of the virus. In the year ending 31st March 2019, 116,940 DoLS applications were granted in care homes or hospitals. Lewis suggests that the local authority - the public agency who makes the application for DoLS - has an ongoing duty to ensure that detention remains in the person's 'best interests'; it is likely to be failing to do this in the circumstances described here.

In some Finnish care homes, residents with dementia had their liberty curtailed by being refused access to certain areas of the home; some were even stopped from moving around at all (Valayudhan et al., 2020). This may be deemed inhuman treatment (See Article 3) especially where wandering is a symptom of a person's dementia and is known to reduce distress. The locking of doors of quarantine or isolation rooms not only denies the resident their liberty but places them at risk of harm regarding falls and leaving the room in the event of a fire. It is a form of imprisonment. In response to many complaints from families in the first few weeks of the pandemic, the Parliamentary Deputy-Ombudsman ruled that, 'When locking the door (of a room), compliance with the law requires that the person with dementia has the actual and effective possibility to contact the personnel. If a person is not independently capable of contacting personnel, the personnel must be continuously present' (Parliamentary Ombudsman of Finland, 2020). It is hard to imagine that one to one, 24-hour care would be possible to offer in understaffed care homes.

In Spain, several residents with advanced dementia were physically restrained to comply with Covid-19 safety regulations such as hand washing; some were even moved to an unfamiliar care home to be supported in isolation care 'for their own protection' (Mallet et al., 2020). These decisions were not discussed with the resident or their families; on occasion the family was not even told that their relative had been moved. This evidence, and that reviewed in other Articles, suggests that throughout the pandemic 'safety and protection' has been prioritised over the liberty and security of residents (Giebel et al., 2020a).

Article 8: right to respect for private and family life

One of the most common features of 'risk reduction' adopted by care homes was to completely stop, or severely restrict, visits by relatives. In Finland, after a state of emergency was declared on March 16th, there was a prohibition of visits to care homes; even when the state of emergency ended, restrictions remained in place (Ministry of Social Services and Health, 2020). Similar restrictions were implemented in the UK, Spain, and Ireland (McGarry et al., 2020).

This practice has had several negative consequences. Family members often (continue to) provide practical, physical, and psychological care to their relative in the care home (Larkin & Milne, 2017). During the pandemic, this care was no longer available, resulting in many residents receiving lower levels of care and attention; it also disrupted the 'usual rhythm' of care.

Not seeing relatives also has significant mental health consequences (Gonzalez, 2020). A recent rapid review of the impact of visitor exclusion found that residents experienced higher levels of depression, anxiety, isolation, and loneliness (Comas-Herrara et al., 2020; Valayudhan et al., 2020). Irish practitioners have highlighted the loss of residents' sense of 'connection' to their families and communities; this connectivity is an especially important dimension of Irish culture (Brennan et al., 2020). For residents with dementia lack of contact and social engagement can lead to deterioration of behavioural symptoms (Gonzalez, 2020).

As mentioned previously, in addition to families being excluded from visiting care homes, the UK government also suspended oversight visits from the CQC during the pandemic. The decision to exclude both family and CQC visits contributes to care homes becoming (more) closed as institutions. It makes it less likely that residents gain access to health care (see above); it also increases

the risk of abuse and neglect and makes it less likely that abuse will be identified or investigated (Amnesty International, 2020).

Article 14: general prohibition of discrimination

Whilst Article 14, speaks to the general prohibition of discrimination, it does not explicitly refer to discrimination based on older age as a violation of human rights. However, most European countries have national legal frameworks that protect against age discrimination; this reflects acceptance of the EU principle of 'equal treatment between persons irrespective of age', particularly in the areas of social protection, employment, and access to services (European Union/78/EC, 2000).

It could be argued that the treatment of care homes, and care home residents, throughout the pandemic has been discriminatory; most of the examples of human rights violations are, in essence, examples of discrimination. In her review of deaths in UK care homes Milne (2020) concludes that, 'care home residents are simply not considered to be important enough to justify the deployment of resources, to be protected or be included in pandemic planning'. Commentaries on the care home scandal use the term 'abandonment' repeatedly (Alzheimer's Society et al., 2020; Chakelian et al., 2020): 'abuse' and 'neglect' are also employed in some media reports and academic papers (Hull, 2020; Jolly, 2020; Murray, 2020; Trabucchi & De Leo, 2020).

At the height of the pandemic, there were concerns about how health services would cope with the rising numbers of patients in a critical condition and questions were raised about how older patients might be 'triaged' to ensure that resources could be used most effectively (Bagenstos, 2020). This was age discrimination by the back door; 'clinical' tools and assessments were used to disadvantage, or even exclude, older people from accessing the health care they needed (Matteo & Proietti, 2020). In Ireland, accusations of discrimination have been levied at the government because of its 'almost exclusive' focus on acute hospitals (Conneely, 2020). The Irish Health Information and Quality Authority highlighted that there was 'No national clinical oversight of some of our most vulnerable citizens' in care homes during the pandemic (HIQA Report to Oireachtas Committee, 2020, p77). In the UK both the government and public agencies, including Public Health England and the Care Quality Commission, have been heavily criticised for their 'discriminatory' attitudes towards older people and their abandonment of care home residents (Phillipson et al., 2020; Skoura-Kirk, 2020).

In terms of specific examples of overt age discrimination, the Madrid (Spain) media reported instructions, given to emergency services, to 'avoid transferring care home residents to hospitals', almost all of which had a shortage of intensive care beds and ventilators. Guidelines, sent to nursing homes by Madrid's Department of Health in March, state that residents showing symptoms of respiratory infection who either cannot move independently, have a severe intellectual disability, or have a severe comorbidity should 'not be sent to hospital' (Rada, 2020). In the province of Milan care home residents were not offered tests until late March, because of a decision 'not to test the elderly' (Privitera, 2020). These are clear examples of discrimination and complement the arguments made earlier in the paper, particularly relating to Articles 2 and 3.

It is ironic that whilst there is widespread recognition that older age and ill health are risk factors for Covid-19, care home residents, who are both elderly and have health problems, were directly and indirectly discriminated against in most European countries' planning and response to the pandemic (Xiaonan & Hong, 2020). Some would say that this reveals the deep and embedded nature of ageism and age discrimination in European care systems, cultures and societies and that Covid-19 has simply made visible, and magnified, what was already there.

Discussion

The evidence reviewed supports existing calls for human rights issues for care home residents to be recognised and responded to. Amnesty International's (2020) report '*As if Expendable: the UK government's failure to protect older people in care homes during the Covid-19 pandemic*' is a prominent

example. It summarised the situation thus: '… UK government, national agencies and local level bodies have taken decisions and adopted policies during the pandemic that have directly violated the human rights of older residents in care homes'. Its key messages can be applied to all of Europe. We acknowledge that there are gaps in our data, and we have drawn on material from some countries more than others; this reflects the varied quantity, quality and availability of evidence.

Care homes are part of a wider health and care system. Whilst these systems may differ to some degree in our sample countries, Covid-19 has exposed serious long term structural deficits across all seven (Pollock et al., 2020). Very limited national attention is paid to care homes, they are poorly resourced and funded, and the sector is fragmented and infrastructurally weak. Care homes are separated from health care services in terms of provision, funding, and governance. This lack of connectivity, the profit driven nature of the care home industry, and the invisibility of care homes in the public consciousness combine to position care homes out of the reach and protection of national and European legislation, including that pertaining to human rights.

One of the barriers to enhancing the human rights agenda, is the inability of many people, including policy makers and care providers, to conceptualise that rights 'belong' to older people (Anand et al., 2013). A related challenge is the form those rights take, especially in relationship to care home residents (Cahill, 2018; Milne, 2020a). Whilst there are specific United Nations conventions relating to rights for children, disabled people and women, no specific convention yet exists for older people, (Age International and Age UK, 2015). The lack of recognition, definition and implementation of human rights for older people is - paradoxically - aided and abetted by ageism (Duffy, 2016). Institutional and structural ageism undermine both the nature and delivery of rights for older people and reframes mandatory rights as optional, specifically in times of crisis (Anand et al., 2013).

Social Work and Care Homes: A call to arms

That European states have failed to uphold even the most basic human rights of its care home residents should act as a call to arms for social workers. It is the role of social workers to support older people with long term care needs, protect older people at risk from harm, address both systemic and care related discrimination, and advocate for older people's legal and human rights (Brennan et al., 2020). There is little evidence that these roles were enacted during the pandemic and the critical voices of social workers have been largely absent. Whilst official statements from representative organisations, such as the British Association of Social Workers, have condemned the treatment of residents and joined the call for a public enquiry into care home deaths, this has had limited traction in practice and there has been little discussion about 'actions' relating to how social workers as a profession plan to address care home issues going forward.

For social workers to engage (more) with care homes a challenge needs to be mounted against the current narrow role the state has carved out. A new broader role needs to be imagined and then demanded. There are a number of facets to this role, including - potentially - advocating for the rights of care home residents, working with families e.g. running a relatives group, helping with training of care staff and managers e.g. regarding new legislation, supporting the admissions process beyond the purely transactional, preventing and addressing issues of abuse and neglect, monitoring the quality of care, and being a trusted professional the care home can engage with outside of 'a safeguarding alert' or a crisis admission from hospital. It is part of a social worker's role to challenge care practice that is abusive; it is also their role to address abuse arising from the failure of a care setting to protect an older person from harm, and what Jolly (2020) terms 'statutory neglect' - neglect arising from legal and policy related systems and structural deficits.

The adoption of a critical and radical approach to social work with care home residents is called for across Europe (Banks et al., 2020). Social workers need to reclaim their human rights mandate (Donnelly & O'Brien, 2020; Pentaris et al., 2020). It is time, and timely, that social workers, and

their employers, respond to this call to arms for the sake of the lives and wellbeing of residents and their families and the professional credibility of social work with older people.

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