

Fairer Care at Home

The covid-19 pandemic: a stress test for
palliative and end of life care in Scotland

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Executive summary

Where people die, and the quality of care that they receive towards the end of life, matters. Understanding patterns of where people die is essential to support health policies, resource allocation, and planning and commissioning of services. This is especially important right now because of the major shifts in place of care and death during the pandemic, and the underlying trends in population ageing which mean that deaths (and therefore palliative care needs) will increase substantially over the next 20 years.

Inequalities in where people die have been well described. In many high-income countries, people who live in more deprived areas are more likely to die in hospital, and less likely to die in hospices. Since the start of the covid-19 pandemic, there has been a sustained increase in the proportion of people dying at home across the UK. The reasons for this are unclear. How the pandemic has changed inequalities relating to the place of death is not known, but is essential to guiding the planning of care and ensuring services are fit for the future. We need to know if inequalities have changed and, if so, how.

This is the second report from the Better End of Life programme. The Better End of Life programme is a collaboration between Marie Curie, King's College London Cicely Saunders Institute, Hull York Medical School, the University of Hull, and the University of Cambridge. We used routinely

collected data to explore whether the pandemic uncovered (or amplified) deprivation-related inequalities in the place of death in Scotland.

Key findings

The number and proportion of people who died at home in Scotland from March to December 2020 increased compared to 2019, for both men and women. Before the pandemic, in 2019, people living in the most deprived areas were more likely to die at home than those in least deprived areas. In 2020, deaths at home increased for all socioeconomic groups; however, the increase in deaths at home was smallest for people living in the most deprived areas and greatest for people living in the least deprived areas.

This inequality was apparent for people who died between the first two pandemic waves. This was a period of relatively stable mortality levels with fewer covid-19 deaths; therefore this finding indicates a change that may be sustained beyond the pandemic.

Few deaths where covid-19 was listed as a cause of death occurred at home. This suggests that the changes observed were not a direct consequence of covid-19 infection, but resulted instead from indirect consequences of the pandemic; such as changes to the way people accessed services and disruption to the health and care system.

Rashmi Kumar, PPI member, reflects on the findings of this report

My mother sadly passed away during the pandemic. During her last months of life I was advised again and again by 111 services that I should take my mother to hospital, to A&E, if I needed support. However, having been in hospital previously, her preference was to stay at home. It was only with the support and guidance of my two nieces, who are both doctors, that we were able to look after my mother at home.

This report identifies the urgent need for investment in community care. Unless this is done quickly, it will be too late for too many people and families. More people will continue to suffer, health inequalities will widen, and the mental health impact of bereavement will get worse. Change is needed now, not in years. Lives are being lost today, and communities are suffering in silence.



Future priorities

In this report we provide the first evidence that the increase in deaths at home that occurred during the pandemic was accompanied by a widening of socioeconomic inequality. We call for:

Investment in primary care, community and palliative care services, to ensure high quality and equitable care at the end of life, to meet the growing demand for these services

Everyone should have the opportunity to receive the best possible care at the end of life, in the place of their choosing. To ensure good quality of care at home, investment in primary care, community and palliative care services is needed. We must do this in a way that reduces rather than exacerbates inequalities. Ongoing monitoring of place of death trends and inequalities is essential.

Embedding of outcome measures to drive learning and improvement

Understanding the quality of end of life care across settings is essential to guide resources

and support. Routine collection and monitoring of outcomes data that is meaningful for those approaching the end of life should be implemented to identify unmet patient and carer/family needs and concerns. Linkage to nationally collected health and mortality data would be transformative for monitoring inequalities and improving the quality of care.

Investment in multi-disciplinary research to further understanding and improvement

More research is needed to understand how the lasting effects of the pandemic have shaped experiences for dying patients and their carers, in particular quality of care and whether individuals' preferences have been met. Investigating the mechanisms driving the increase in deaths at home, widening inequality, and exploring factors such as ethnicity, housing quality, social support and finances, is essential to inform delivery of effective and equitable services, fit for the future.

Introduction

The circumstances in which people are born, live, work and age are known to affect health and care outcomes⁽¹⁾. Health is closely linked to income, education, ethnicity and area of residence. Understanding these factors is essential when planning equitable health and care services.

The 2020 Marmot report 'Build Back Fairer' highlighted the disproportionate effect that the covid-19 pandemic had on social and economic groups⁽²⁾. Individuals living in areas of high deprivation, with poor housing conditions, and those from Black, Asian and minority ethnic groups were more likely to die from covid-19. The 2020 Marmot report argued that the pandemic had exposed the underlying inequalities in society, and amplified them. The report considered the impact of the pandemic on mortality, and physical and mental health, but not on end of life care.

Understanding where people die, and the drivers of this, is essential to support health policies, resource allocation, and planning and commissioning of services. This is increasingly important right now because of the major shifts in place of care and death during the pandemic⁽³⁾, and the underlying trends in population ageing, which mean that deaths (and therefore palliative care needs) will increase substantially over the next 20 years^(4, 5). This will have notable implications for formal service provision as well as informal (unpaid) care.

Understanding where people die is also important because many people who express a preference say that they would prefer to die at home⁽⁶⁾, though other aspects of care can be more important⁽⁷⁾. In addition, preferences can change and may be influenced by social circumstances, such as income, ethnicity, housing and social support. Without adequate care and support, deaths at home may not be a positive experience.

Inequalities in where people die have been well described globally⁽⁸⁾. In England and Wales, people who live in more deprived areas are more likely to die in hospital, and less likely to die in hospices^(9, 10, 11). Less is known about inequalities in where people die in Scotland or Northern Ireland. Since the start of the covid-19 pandemic, there has been a sustained increase in the proportion of people dying at home⁽³⁾. We know little about what has driven this, though there is some evidence that fears of infection and visiting restrictions contributed to more people remaining at home to die⁽¹²⁾. Whether the pandemic uncovered (or amplified) inequalities relating to the place of death is not known.

The report uses mortality data for Scotland to ask *"Did the pandemic uncover (or amplify) inequalities relating to the place of death?"*, and *"What are the implications for research, and health and care policy?"*.

Changes in place of death during 2020 in Scotland

We included 60,526 deaths that occurred during 2020 in Scotland; overall 30.3% of these were at home. Figure 1 shows place of death during 2020, and compares this with baseline data from 2019.

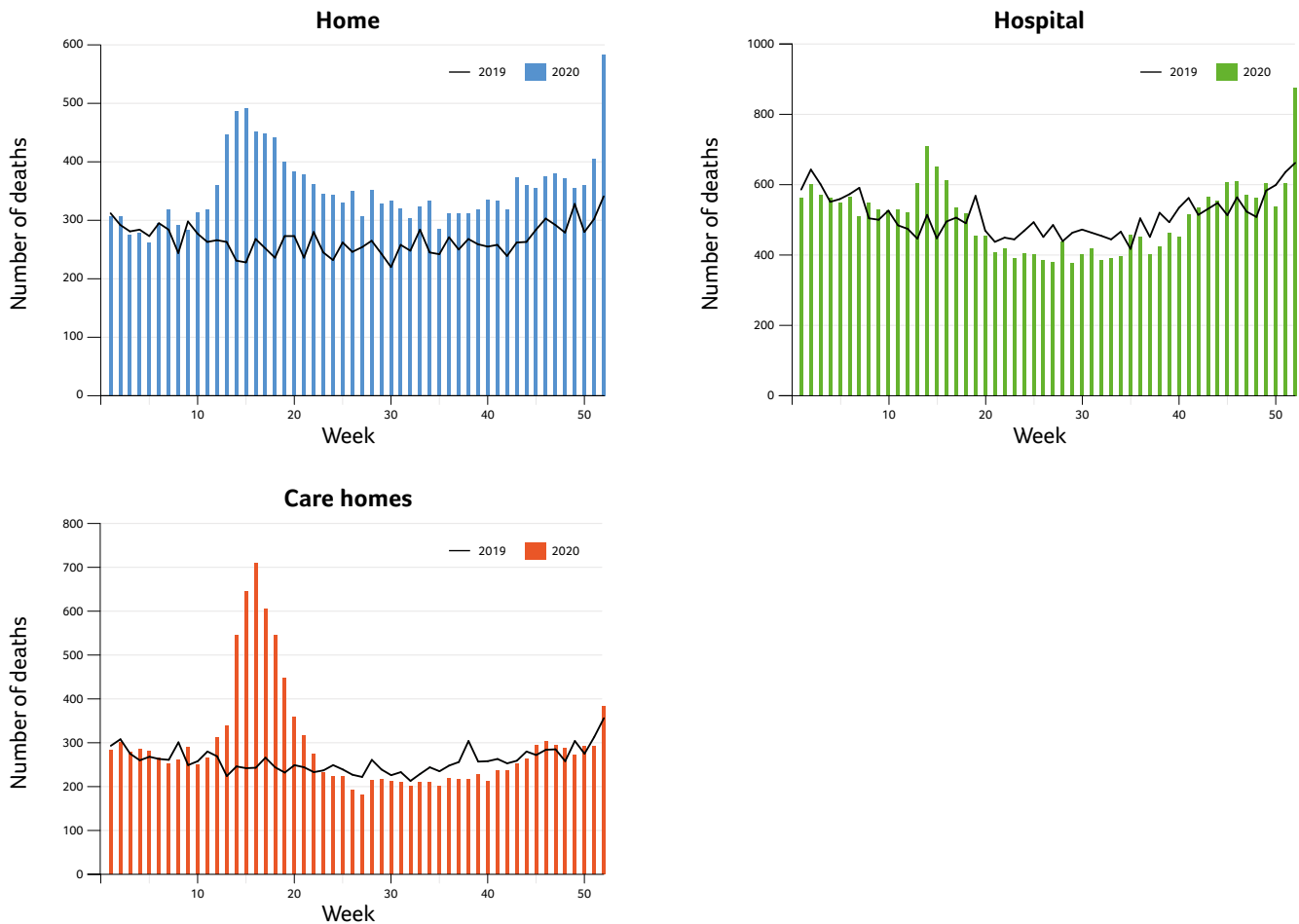
During the first wave of the covid-19 pandemic (weeks 14 to 23 of 2020), there was an increase in the weekly number of deaths at home, in hospital and in care homes compared to 2019 baseline levels. Care home and hospital deaths

subsequently fell to or below baseline levels. However, deaths at home remained higher than baseline levels for the duration of 2020.

Figure 1. Number of deaths by week and place of death in Scotland 2019-20

*note, hospice deaths are included in the care home category

*note, scales vary



METHODS BOX

Mortality data were provided by the National Records Office for Scotland, accessed through a Trusted Research Environment. We used data on deaths in 2019 and 2020. We defined the first wave as from 28 March to 30 May 2020 and the inter-wave period from 31 May to 17 October 2020⁽¹³⁾. We excluded external causes of death and deaths among people whose usual place of residency was not Scotland.

We used the postcode from the decedent's place of residence to link to the level of deprivation using the Scottish Index of Multiple Deprivation (SIMD) 2020. Observations missing geographical information were removed. Place of death was classified as home or other, using the place of death category "non-institutional deaths". We obtained information on covid-19 related deaths using ICD-10 codes U07, U09 or U10. We were unable to include information on ethnicity due to a high level of missing data. We used Poisson regression models with robust standard errors to report the proportion of deaths at home, adjusted by age and sex, using SIMD quintiles.

Deaths at home during 2020 in Scotland

To understand how deaths at home changed during the first pandemic wave, and the months after it, we extracted data on all deaths in Scotland between 28 March and 31 December 2020 and compared to baseline (2019).

- Between 28 March and 31 December 2020 there were 46,372 deaths (Table 1). Overall the number and proportion of deaths at home were higher during 2020 than for the same period in 2019 (10,433 or 25.6% in 2019; 14,538 or 31.4% in 2020).
- The proportion of people dying at home in 2020 was higher than in 2019 for both men and women.
- The proportion of people dying at home in 2020 was higher than in 2019 for people in all deprivation groups, with the largest absolute difference in the least deprived groups.
- 399 (6.0%) of deaths where covid-19 was mentioned on the death certificate were at home.

Table 1: Characteristics of people who died at home in Scotland between 28 March and 31 December 2019-20

	28 March to 31 December 2019			28 March to 31 December 2020		
	Total number deaths	Deaths at home n	%	Total number deaths	Deaths at home n	%
Total	40,694	10,433	25.6%	46,372	14,538	31.4%
Age (mean, sd)	77.4 (13.7)			77.5 (13.6)		
Sex						
Male	19,517	5,711	29.3%	22,898	7,851	34.3%
Female	21,177	4,722	22.3%	23,474	6,687	28.5%
Deprivation (SIMD)						
1 (most deprived)	9,538	2,700	28.3%	11,163	3,685	33.0%
2	8,935	2,415	27.0%	10,353	3,346	32.3%
3	8,674	2,157	24.9%	9,515	2,899	30.5%
4	7,259	1,718	23.7%	8,228	2,535	30.8%
5 (least deprived)	6,288	1,443	23.0%	7,113	2,073	29.1%
Covid-19 on death certificate						
No				39,687	14,139	35.6%
Yes				6,685	399	6.0%

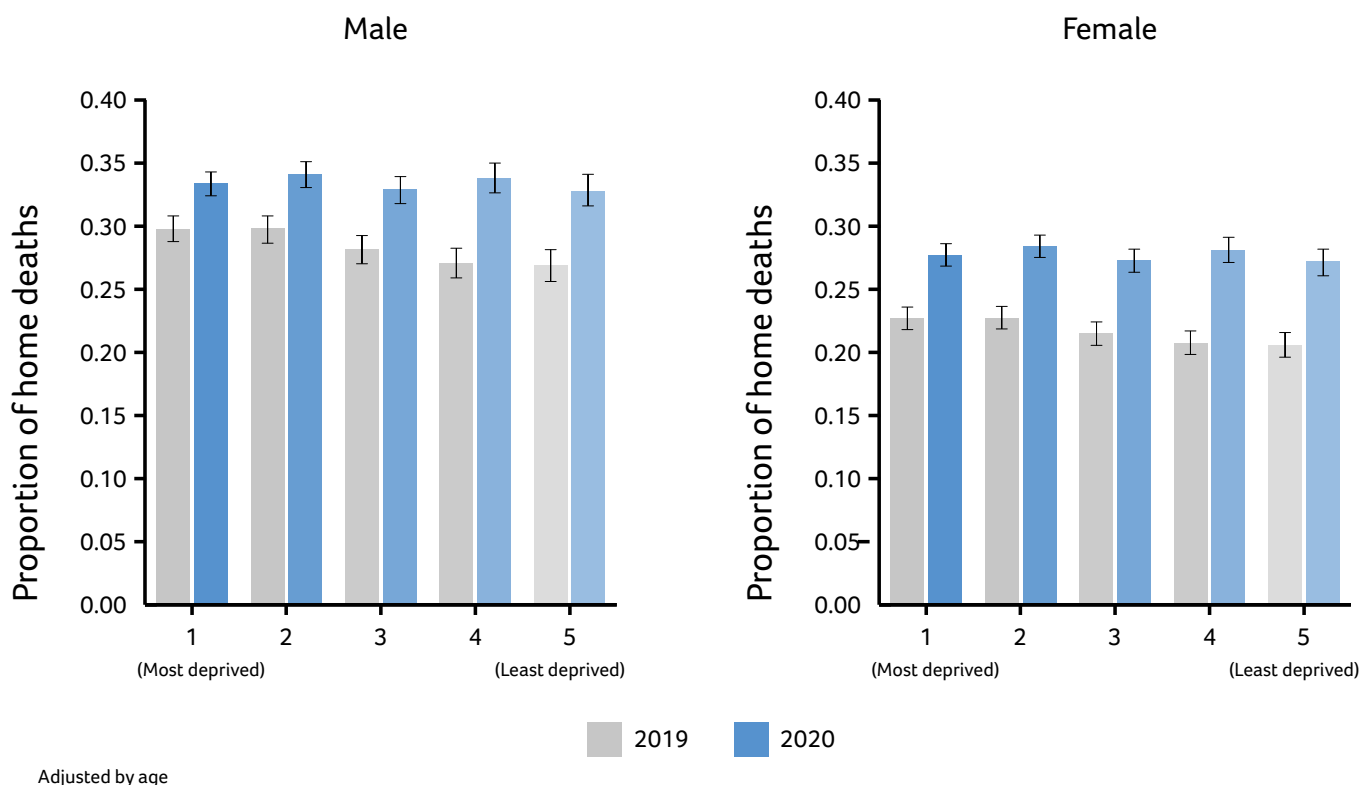
The association of socioeconomic position with deaths at home

To compare deaths in 2019 with deaths in 2020, data were adjusted by age and sex (see Methods box).

- Among men and women who died in 2019, the adjusted proportion of deaths at home was lower for those living in the least deprived areas, and was lower for women than men (Figure 2).
- During 2020 deaths at home increased across all deprivation groups and among both men and women. The magnitude of the increase varied, with the most deprived groups (groups 1 and 2) experiencing the smallest increase in deaths at home, and the least deprived groups (groups 4 and 5) experiencing the largest increase in deaths at home.

Figure 2. Adjusted proportion of deaths at home by deprivation and sex in Scotland

Deaths between 28 March and 31 December in 2019 and in 2020. Deprivation was derived using quintiles from the Scottish Index of Multiple Deprivation (SIMD)



KEY MESSAGE

While deaths at home increased during the covid-19 pandemic across all deprivation groups, the increase was smallest for people in the most deprived groups and greatest for people in the least deprived groups.

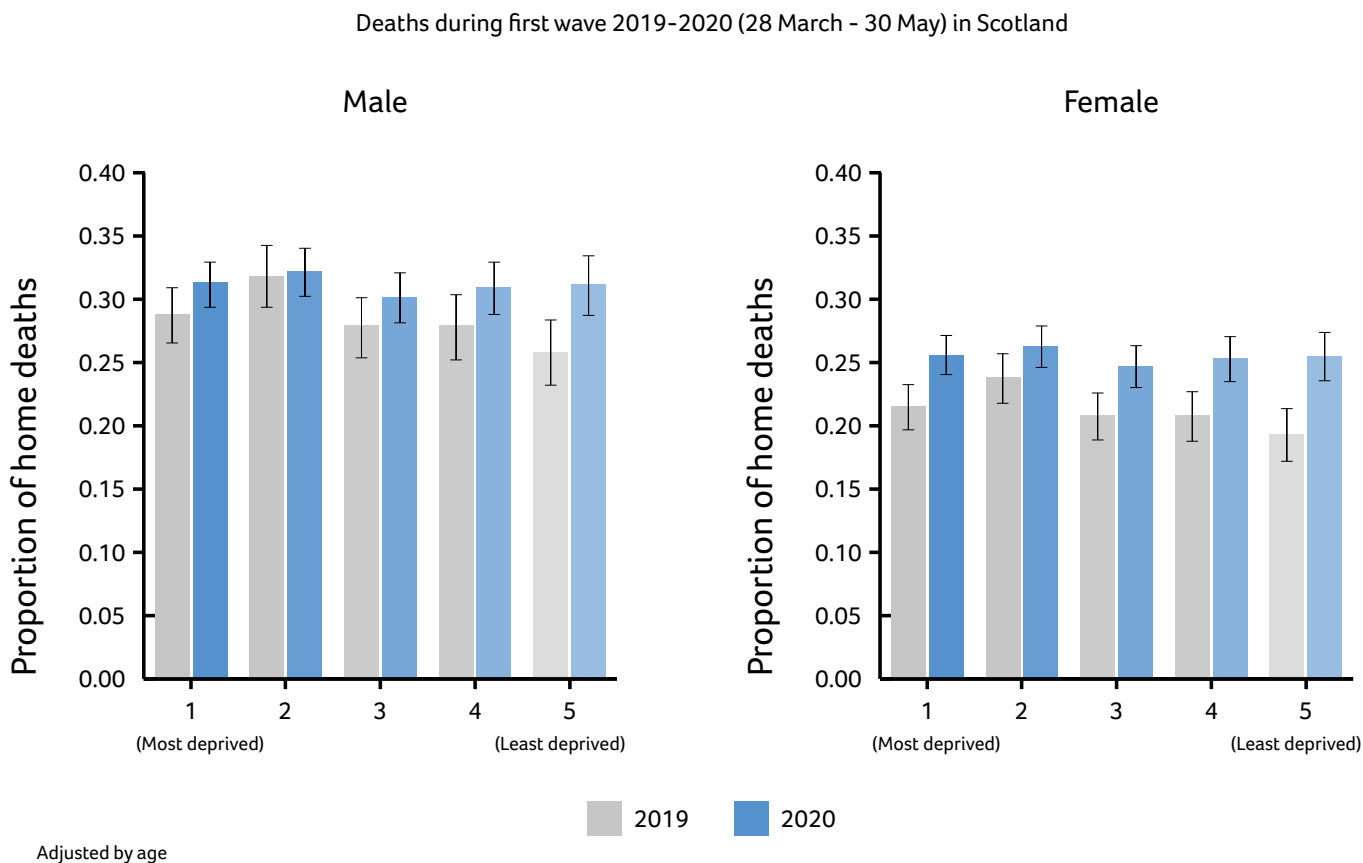
We were interested in understanding changes that occurred during the ‘inter-wave period’ specifically. This was a period when deaths in hospital and care homes fell to pre-pandemic levels, but there was a sustained increase in deaths at home. The inter-wave period is important to examine because it is most relevant

to understanding service and support needs post-pandemic.

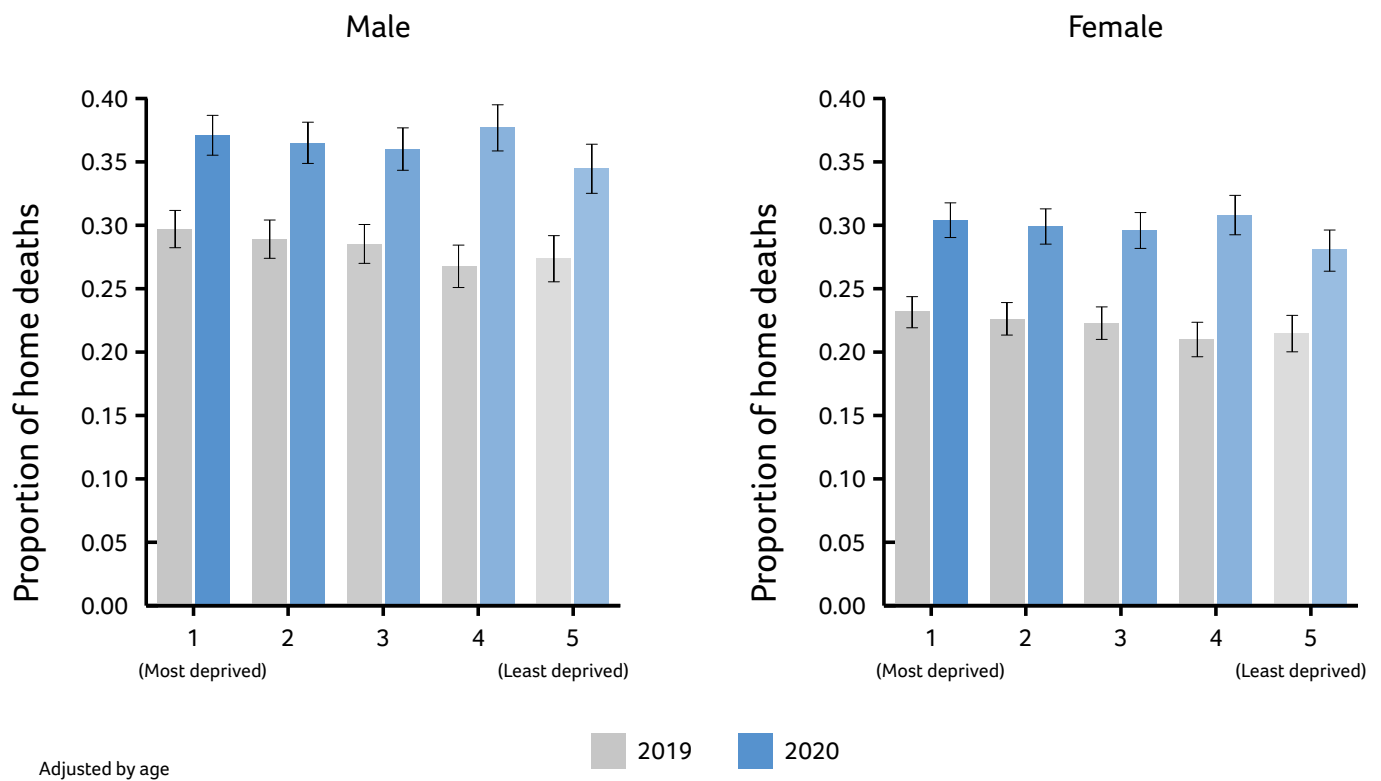
- During the inter-wave period, deaths at home increased across all deprivation groups and among men and women (Figure 3). This was greatest for the least deprived groups, particularly group 4.

Figure 3. Adjusted proportion of deaths at home by deprivation and sex, for first wave and inter-wave period in Scotland

Deaths in 2019 and 2020 during first wave (28 March to 30 May) and inter-wave period (31 May to 17 October) Deprivation was derived using quintiles from the Scottish Index of Multiple Deprivation (SIMD)



Deaths during inter-wave 2019-2020 (31 May to 17 October) in Scotland



KEY MESSAGE

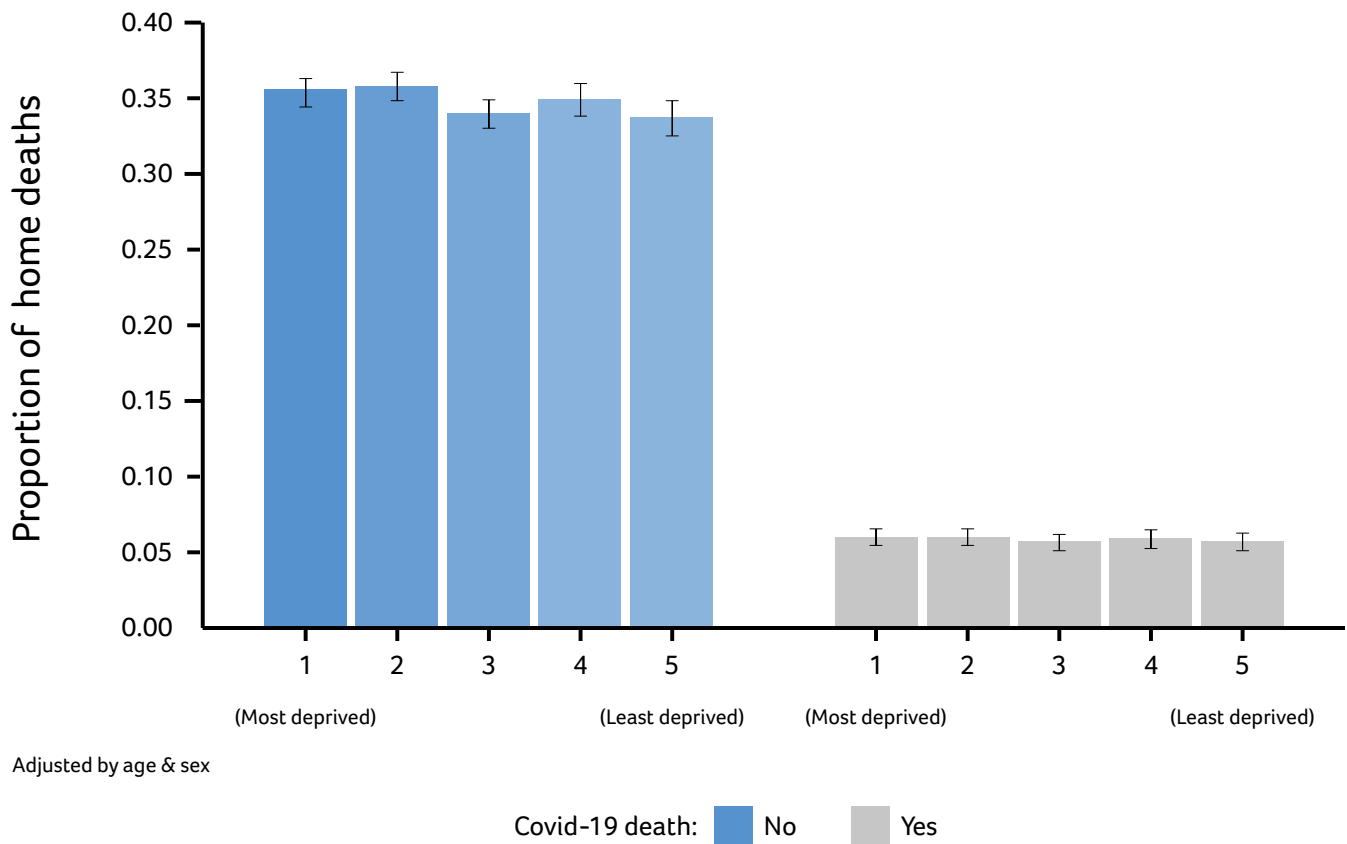
The identified socioeconomic inequality in deaths at home was apparent during the inter-wave period. This is important because this was a period of stable mortality levels and few covid-19 deaths, and may therefore indicate changes that will be sustained beyond the pandemic. However, the lack of a clear gradient or trend means this finding should be interpreted cautiously.

We also wanted to understand the relationship between socioeconomic position and deaths at home, according to whether or not covid-19 was mentioned on the death certificate.

- A small proportion of people who had covid-19 on their death certificate died at home (Figure 4). We found no deprivation trend in the population where covid-19 was mentioned as a cause of death. However, community testing for covid-19 was scarce during the early pandemic, meaning this finding should be interpreted cautiously.

Figure 4. Adjusted proportion of deaths at home by deprivation and covid-19 deaths

Deaths between 28 March and 31 December 2020. Deprivation was derived using quintiles from the Scottish Index of Multiple Deprivation (SIMD)



KEY MESSAGE

Few deaths where covid-19 was mentioned as a cause of death occurred at home. This suggests that the identified socioeconomic inequality in deaths at home was more likely to be a consequence of changes that happened during the pandemic period, rather than a direct consequence of covid-19 infection. However, inconsistent testing (and death certification) in the community means this finding should be interpreted cautiously.

Conclusions

The 2020 Marmot report ‘Build Back Fairer’ suggested that the covid-19 pandemic had *exposed the underlying inequalities in society, and amplified them*, but did not examine inequalities relating to end of life care. Our findings indicate that the covid-19 pandemic may have exposed and amplified inequality relating to the place of death in Scotland, with deaths at home increasing least among people in the most deprived groups, and most among people in the least deprived groups.

Patterns in the place of death have been relatively little studied in Scotland. A report examining place of death among people with cancer in Scotland (2009-2018) found that people living in more deprived areas were more likely to die at home, consistent with the patterns we found for 2019⁽¹⁴⁾. Further research is needed to better understand the determinants of deaths at home in Scotland, including the interaction with deprivation, ethnicity, housing quality and social support. Due to missing data, information on ethnicity was not included in our analysis, and should be explored where possible in future research. Understanding how preferences and quality of care changed during the pandemic is essential.

When health services are under strain, inequalities emerge and people who are more deprived are often disadvantaged. We found that during the pandemic, deaths at home increased most among the least deprived groups. Policy and health service changes, as well as preferences to avoid hospice or hospital admission (because of fears of infection and visiting restrictions), are likely to have contributed to the increase in deaths at home overall. It may be that people in the most deprived groups did not always have the necessary resources (such as appropriate housing, social support, financial security, informal carers, primary care and community services) to support death at home.

We know that deaths and palliative care needs in Scotland are projected to increase rapidly over the next 20 years. Better resourcing of community health and care services is urgently needed. This includes specialist palliative care services, which

enable deaths at home and improve quality of care at the end of life, as well as primary care and social care services^(15, 16). Ongoing monitoring of place of death trends and inequalities is essential.

Where people die, and the quality of care that they receive, matters. Everyone approaching the end of their life, regardless of their socioeconomic circumstances, should have the care and support they need, in the place of their choosing. The pandemic was a ‘stress-test’ for palliative and end of life care. Future demographic changes in Scotland mean that without better resourcing of services, inequalities that emerged during the covid-19 pandemic are likely to increase. The data in this report calls for careful attention to ensure care and support for people approaching the end of life that is equitable, tailored to their needs, and fit for future demographic changes.



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Appendix

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